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Design and Operation of the National Survey of Children with Special Health Care Needs, 2001

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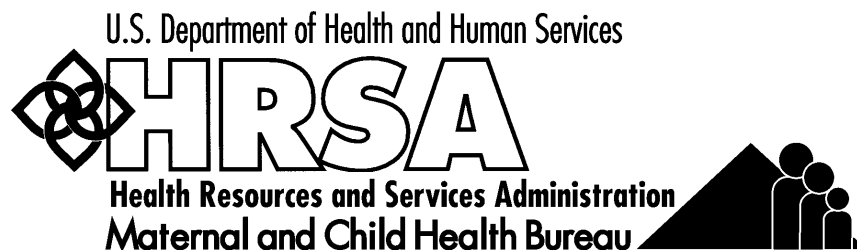
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Abstract

Objectives—This report presents the development, plan, and operation of the National Survey of Children with Special Health Care Needs (CSHCN), a module of the State and Local Area Integrated Telephone Survey, sponsored by the National Center for Health Statistics, Centers for Disease Control and Prevention. This survey was designed to produce national and state-specific prevalence estimates of CSHCN, describe the types of services that they need and use, and assess aspects of the system of care for CSHCN. This study included two additional modules to provide health care coverage estimates for all children and to collect data on the reasons that low-income uninsured children lack health care coverage. Primary funding for this survey was provided by the Maternal and Child Health Bureau, Health Resources and Services Administration. Additional funding was received from the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services and from the Missouri Department of Health and Senior Services.

Methods—A random-digit-dial sample of households with children less than 18 years of age was selected from each of the 50 states and the District of Columbia. All children in each identified household were screened for special health care needs. Depending on the health care needs of the children in each screened household, a detailed interview was conducted for one randomly selected child with special needs and a brief health insurance interview was conducted for one randomly selected child without special needs. The respondent was the parent or guardian who knew the most about the child's health and health care.

Results—A total of 196,888 household screening interviews were completed from October 2000 to April 2002. This resulted in 38,866 completed special-needs interviews and 176,296 completed health insurance interviews for children without special needs. The weighted overall response rate for special-needs interviews was 61.0%.

Introduction

Through a block grant system to create federal-state partnerships, government Title V funds are available to help states develop and provide coordinated systems of care for children with special health care needs. While most states provide some sort of special-needs care using these funds, formal evaluation of the special-needs programs has proved challenging for two reasons: 1) no single method of identifying these children, or operational definition of special health care needs, has been accepted; and 2) states vary considerably in the levels and types of services provided. Yet, state-level data regarding the need for, use of, and barriers to care are necessary for accurate program evaluation. The National Survey of Children with Special Health Care Needs (CSHCN), detailed in this report, was designed to produce prevalence estimates of CSHCN using a standard battery of screening questions, describe the types of services that these children need and use, and assess possible areas of improvement in the system of care for CSHCN (van Dyck et al., 2002). For the first time, this information is available at the state level, collected in a manner that allows comparison across states and nationally.

State and Local Area Integrated Telephone Survey Program

The National Survey of CSHCN was conducted as a module of the State and Local Area Integrated Telephone Survey (SLAITS). The SLAITS program, sponsored by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), is a broad-based, ongoing surveillance system available at the state and local levels for tracking and monitoring the health and well-being of children and adults. SLAITS uses the same sampling frame as the National Immunization Survey (NIS), which is conducted jointly by NCHS and the CDC's National Immunization Program (Ezzati-Rice et al., 2000a). The NIS is a large-scale random-digit-dial (RDD) telephone survey that screens for the presence of young children in sampled households and collects vaccination history information for eligible children. The size of the NIS sample provides an economical opportunity to survey other populations in addition to the rare population that eventually screens into the NIS itself. Through the NIS sampling frame, SLAITS modules enjoy cost savings by avoiding some of the expense of frame development, sample selection, and screening.

History of the SLAITS Program

SLAITS began in 1997 with a pilot test in two states, Iowa and Washington, of a series of questions on health, including issues of access to care, health status, and insurance. In 1998, a SLAITS module concerning child well-being and welfare issues was implemented using three samples: a general RDD sample of children in Texas, known Medicaid program participants in Texas, and known Medicaid or MinnesotaCare participants in Minnesota. In 2000, SLAITS fielded the National Survey of Early Childhood Health, which collected data regarding parents' perceptions of their young children's pediatric care and examined relationships between the promotion of health in the pediatric office and promotion of health in the home (Blumberg et al., 2002).

The National Survey of CSHCN, the fourth study in the SLAITS series, was designed to collect data on CSHCN, children's health insurance coverage, and uninsured children from low-

income households. It is the first SLAITS study to take advantage of the full NIS sampling frame to produce state-level estimates.

Background

The National Survey of CSHCN was funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration. MCHB, established in 1935 as part of Title V of the Social Security Act, is charged with the responsibility of protecting the health of mothers and children through the development of programs and systems of care for those populations.

The 1989 Omnibus Budget Reconciliation Act enhanced the Maternal and Child Services Programs' mission with specific provisions for CSHCN, including improved access to care to be monitored by state agencies (Ireys & Nelson, 1992). Today, Title V is administered by MCHB using block grants to create federal/state partnerships to provide family-centered, community-based, coordinated systems of care for CSHCN. A minimum of 30% of block grant funds must be used to support programs for CSHCN, and specific steps must be taken to improve service delivery for these children and their families. States have considerable flexibility in determining the services to provide and the manner in which they are provided.

To guide the development of appropriate services for children with special needs, MCHB established a work group whose mission was to create a broad and inclusive definition of what constitutes special health care needs. After considering condition-list and functional status-based approaches, the work group decided to adopt a definition based on increased service needs, and to include at-risk children to facilitate program planning (McPherson et al., 1998; Westbrook et al., 1998). The resulting definition is as follows:

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998).

Using this definition and the 1994 National Health Interview Survey on Disability, researchers established an initial special health care needs prevalence rate among children of 15-20 percent (Newacheck et al., 1998). The at-risk population was not included in this estimate as there is no accepted approach to identifying these children. In fact, there is no one accepted method of identifying CSHCN. To augment ongoing research on this subject, the pretest phase of the National Survey of CSHCN used two different batteries of questions to screen households to identify CSHCN (Stein et al., 2001; Bethell et al., 2002b). A description of the pretest findings appears later in this report.

Serving CSHCN requires a broad-ranging system of health and related types of care. These services may include specialty physician care, therapeutic services, family support services and care coordination, durable equipment and assistive devices, a variety of education-related services, and transportation services (McPherson et al., 1998). While states vary greatly in the manner used to provide these services, virtually all provide them to some extent. Accurate assessment of use and barriers to needed care are critical to program planning and evaluation because specific criteria must be met for states to receive block grant monies. "Improved needs assessments will require...statewide data collection systems....Most state special-needs programs will require access to expertise not generally available among current staff if the demand for improved data collection is to be met." (Ireys & Nelson, 1992)

National Survey of Children with Special Health Care Needs

The National Survey of CSHCN, able to collect the required data at the state level in a manner that allows comparison across states and nationally, was a major step toward providing the information necessary to accurately assess state activities and program needs. This survey was designed to achieve 750 completed special-needs interviews in each of the 50 states and Washington, D.C. The major research questions that the National Survey of CSHCN was designed to address were:

- What is the prevalence of special health care needs among children under 18 years of age in each state?
- Are their special health care needs and the concerns of their families being addressed?
- What is the quality of primary, specialty, and ancillary care that children receive?
- Are CSHCN receiving comprehensive care in a medical home?
- What factors are associated with the receipt of better quality, more comprehensive care?
- Do families of CSHCN have adequate insurance to pay for the services that CSHCN need?
- What is the impact of the child's health condition on the family?
- From whom are CSHCN receiving needed care coordination services?

Two additional study modules, described below, examined the following research questions:

- How does health insurance coverage for CSHCN compare with coverage for all children?
- Why do uninsured children from low-income households lack coverage, and are their families aware of Medicaid and the State Children's Health Insurance Program (SCHIP)?

Health Insurance Control Sample

The initial design of the National Survey of CSHCN called for collection of health insurance coverage data for sampled CSHCN only. Given the estimated CSHCN prevalence rate of 15-20%, many households with children would need to be screened in order to identify households with CSHCN. To produce estimates on health care coverage for all children and to facilitate comparison of health care coverage for children with and without special needs, the MCHB and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (DHHS) funded the addition of a health insurance control sample of children without special needs, taking advantage of the considerable number of screened households with children. In households with one or more children who did not screen positive for a special health care need, one such child was randomly selected for the health insurance control sample interview. This interview included insurance coverage questions identical to those administered in the special-needs interview.

Low-Income Uninsured Supplement

With the addition of the health insurance control sample, the National Survey of CSHCN was expected to gather an unprecedented amount of children's health insurance coverage data. Taking advantage of the opportunity provided by this study, ASPE funded a module to gather data for uninsured children from low-income households on their parents' knowledge and use of SCHIP and Medicaid programs. The goal for this module was to estimate the prevalence of

uninsured, low-income children who may qualify for Medicaid or SCHIP but are not enrolled in the program, and to determine the reasons why these children are not enrolled. Regardless of special-needs status, all sampled children who were uninsured and who resided in a household with an annual income below 200% of the DHHS Federal Poverty Guidelines received the Low-Income Uninsured Supplement. Eligible children without special needs were also asked a subset of health care access and barrier questions from the special-needs interview.

The data collected with this supplement supported the Department's evaluation of the SCHIP program, as mandated by Congress in the Balanced Budget Refinement Act of 1999. Congress stipulated that the Department's evaluation include the collection of information about why many children eligible for SCHIP are not enrolled. Funds for this supplement came, in part, from the Congressional allocation for this evaluation.

Missouri Supplemental Sample

As noted earlier, and described in detail later, the National Survey of CSHCN was designed to achieve 750 completed special-needs interviews in each of the 50 states and Washington, D.C. Each state also had the option of requesting and funding additional special-needs interviews, in order to produce more precise estimates within their state. The Bureau of Special Health Care Needs in the Missouri Department of Health and Senior Services was the only state agency that exercised this option. In order to accommodate Missouri's request for an additional 750 special-needs interviews (for a total of 1500), a separate supplemental sample was created. This sample was fielded independently of the NIS, but otherwise was fielded using the same methods and questionnaire as other National Survey of CSHCN sample. The purpose of the Missouri supplemental sample was to provide data on the prevalence, health care needs, and impact of special health care needs in the state. Therefore, health insurance control sample interviews and Low-Income Uninsured Supplement interviews were not administered to households in this sample. Households with children in this sample completed only the National Survey of CSHCN special-needs screening and special-needs interview, as applicable.

Sample Design

Like all SLAITS modules, the National Survey of CSHCN took advantage of the large number of screening calls required for the NIS. To accomplish the goal of 750 completed special-needs interviews in each state, telephone numbers were initially selected from the telephone numbers randomly generated for the NIS screening effort. Therefore, the procedures for drawing the NIS sample were the first steps in the procedures for drawing the National Survey of CSHCN sample. However, because of the scope of the National Survey of CSHCN, additional sample was necessary to augment the NIS sample in certain states.

The next two sections describe the basic NIS sample design and serve as a non-technical description of the National Survey of CSHCN sample design and allocation procedures. Appendix I of this report includes a more technical description of the National Survey of CSHCN sample design and weighting procedures. For more detail on the NIS sample design, readers are encouraged to obtain chapter 3 of the 1999 *National Immunization Survey Sample Design Report*, which is available from NCHS. Further information regarding the NIS itself can be found in Zell et al.'s *National Immunization Survey: The Methodology of a Vaccination Surveillance System* (2000).

The National Immunization Survey Sampling Plan

The NIS was established to monitor vaccination levels of very young children within geographic areas called Immunization Action Plan (IAP) areas. These 78 non-overlapping IAP areas encompass the entire United States, and each IAP area is within the borders of a single state. Every three months (or calendar quarter), the NIS selects a random sample of telephone numbers in all 78 IAP areas. The NIS screens almost 1 million households per year to identify those containing at least one child age 19 to 35 months. These children are the primary targets of immunization programs. Because only 5% of households in the United States contain children in this age range, a large number of households are screened in order to identify households with eligible children. SLAITS modules use this NIS screening sample.

In the United States, telephone numbers consist of an area code (3 digits), a prefix or exchange (3 digits), and a suffix (4 digits). A random sample of telephone numbers can be chosen by randomly selecting an area code and prefix combination currently in use and appending a randomly chosen four-digit number between 0000 and 9999. This RDD sample would be a simple random sample of telephone numbers from the frame of all possible telephone numbers.

For the NIS, telephone numbers are selected for screening through list-assisted RDD methods. Before the selection of the sample of telephone numbers, banks of 100 consecutive numbers in the same area code and prefix combination that contain zero directory-listed telephone numbers—that is, banks of 100 numbers that have a low probability of containing working residential numbers—are deleted from the sampling frame. For this step, the NIS uses the GENESYS Sampling System (a proprietary product of Marketing Systems Group), which in turn uses a file of directory-listed residential numbers from Donnelley Marketing Information Services (DMIS). A simple random sample of 10-digit telephone numbers is then drawn from the retained banks of 100 numbers. Known business and nonworking telephone numbers are removed from this sample prior to dialing.

Each remaining telephone number is then called by an interviewer, and if it belongs to a household, the person answering the telephone is asked if there are any children 19-35 months of age living or staying in the household. If NIS age-eligible children are in the household, a household respondent is interviewed about each age-eligible child's immunization history and the demographic characteristics of the household. The NIS interviewer also asks for permission to contact the immunization providers of the children to obtain vaccination information from the child's medical record.

National Survey of CSHCN Sampling Plan

The goal of the National Survey of CSHCN sample design procedures was to generate samples representative of the state populations of children both with and without special health care needs. An additional goal of the National Survey of CSHCN was to obtain state-specific sample sizes that were sufficiently large to permit precise estimates of the characteristics of CSHCN in each state. (Sufficient precision was defined as a maximum relative standard error of 10% for all point estimates greater than 15%.)

To achieve these goals, state samples were designed to obtain 750 completed interviews with CSHCN. A target number of health insurance control sample interviews was not set.

Rather, in each household with children that was screened in order to complete the 750 required special-needs interviews in each state, a health insurance control sample interview was initiated if at least one child without special needs was identified. Thus the total number of health insurance control sample interviews was a function of the number of households with children screened.

The number of CSHCN to be selected in each IAP area was determined by allocating the total of 750 children in the state to each IAP area within the state in proportion to the total projected number of households with CSHCN in the IAP area. (The projected number of households with CSHCN in each IAP area was adjusted as needed based on the initial data collected from the survey.) Given this allocation, the number of households that needed to be screened in each IAP area was calculated using the expected proportion of households with children under 18 years of age in the IAP area. Then, the number of telephone numbers that needed to be called was computed using the expected working residential number rate. The number of telephone numbers drawn was increased to compensate for the fact that not all respondents would agree to participate and therefore there would be some degree of nonresponse.

In 14 states (Hawaii, Idaho, Iowa, Mississippi, Missouri, Nebraska, Nevada, New Mexico, Oklahoma, Oregon, South Dakota, Utah, Virginia, and Wyoming), there was insufficient NIS sample available to obtain the desired number of completed interviews for the National Survey of CSHCN. Therefore, additional telephone numbers were drawn using the GENESYS Sampling System, in the same manner described in the section above. Table 1 shows, by state, the proportion of the National Survey of CSHCN sample that was augmented for each state. That is, for each state in Table 1, the proportion listed is the proportion of telephone numbers that were called specifically for the National Survey of CSHCN.

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Because of the repeated quarterly selection of NIS sample in each IAP area, some telephone numbers were selected more than once over the course of the 6-quarter National Survey of CSHCN data collection period. Such numbers were not contacted a second time for the study. Instead, these cases were automatically finalized. Response rates reflect the final disposition of a telephone line from its original sampling.

With the exception of the augmentation sample, each selected telephone number was called and screened for residential status and for the presence of NIS age-eligible children. NIS interviews were conducted if NIS age-eligible children lived in the household. If NIS age-eligible children did not live in the household, interviewers asked if there were any children under age 18 living in the household. Then, regardless of whether an NIS interview was conducted, if children were in the household, a series of questions were asked about their health care needs to determine special health care needs status. If any children in the household were identified as having special health care needs, one was randomly selected (i.e., sampled) for a detailed interview. Similarly, if there were children without special needs, one was randomly selected for a health insurance control sample interview. Therefore, eligible households with children could have either one or two children selected for an interview, depending on the care needs of the children in the household.

Table 1. Augmentation Sample by State

State	Proportion of State Sample Called Only for National Survey of CSHCN
Hawaii	25.8%
Idaho	20.3%
Iowa	2.4%
Mississippi	13.0%
Missouri ¹	45.4%
Nebraska	9.7%
Nevada	17.4%
New Mexico	2.5%
Oklahoma	8.7%
Oregon	2.6%
South Dakota	14.6%
Utah	29.0%
Virginia	17.1%
Wyoming	5.5%

*The proportion in Missouri is larger than the proportion in other states because of the Missouri Supplemental Sample described earlier in this report.

Screening for Special Health Care Needs

One of the main goals of the National Survey of CSHCN was to provide state-level estimates of the prevalence of CSHCN. As mentioned in the introduction to this report, there is no one accepted method of identifying CSHCN. Therefore, careful consideration of the screening methodology for the study was necessary.

Comparing Screening Instruments (Pretest I)

To assist in the decision of which screening instrument to use, an initial pretest was designed to test two different screening instruments developed to identify special health care needs in children. The first instrument—the CSHCN Screener—was developed as part of the Foundation for Accountability’s (FACCT) Child and Adolescent Health Measurement Initiative. The CSHCN Screener includes five stem questions on general health care needs that could be the consequence of chronic health conditions (e.g., need for special therapies, need for prescription medication). If a child currently experiences one of these consequences, follow-up questions determine whether this health care need is the result of a medical, behavioral, or other health condition, and whether the condition has lasted or is expected to last for 12 months or longer. Those with affirmative answers to the stem and both follow-up questions are considered to have a special health care need (Bethell et al., 2002b).

The second instrument was the Questionnaire for Identifying Children with Chronic Conditions-Revised Version (QuICCC-R), developed by Ruth Stein and her colleagues at the Albert Einstein College of Medicine, Yeshiva University (Stein et al., 2001). Like the CSHCN Screener, this instrument also assesses whether a child experiences certain consequences that suggest a special health care need. Rather than five general stem questions, however, the QuICCC-R asks about 16 stem questions designed to capture more specific experiences (e.g., special diets, hospitalizations, special arrangements in school). The series of follow-up questions for most experiences are similar to those for the CSHCN Screener.

Pretest I Methods

Data collection for this pretest took place between March 3 and May 30, 2000. At this time, the SLAITS National Survey of Early Childhood Health was also in the field. Based on the sample requirements necessary for that study, eight states were identified as having sufficient remaining NIS sample for the pretest: Alabama, Iowa, Montana, Nevada, New Jersey, Pennsylvania, Tennessee and West Virginia. Thus, the pretest sample was not expected to perfectly mirror the nationally representative sample used for the main study.

Both screeners were administered in every household with children. To avoid bias related to screener order, the order of screener administration was alternated: In 50.2% of the cases, the CSHCN Screener was administered first, whereas the remaining 49.8% of the cases received the QuICCC-R first. To facilitate the assessment of the screening instruments, in cases where a child screened positive for special health care needs on either screener, an open-ended question asked the respondent to name the type of medical, behavioral, or other health condition that the child had.

In households with at least one child who was identified through the use of either screener as having a special health care need, one such child was sampled and the special-needs

interview was administered. In addition, a subsample of children without special health care needs was administered the health insurance control sample interview. A total of 1,284 households with children were screened, resulting in the completion of 2,420 child-level screening interviews, 445 special-needs interviews, and 606 health insurance control sample interviews. Interviews were conducted only in English. Low-Income Uninsured Supplement interviews were not conducted during this pretest.

Pretest I Results

A detailed description of the pretest results has been published in *Ambulatory Pediatrics* (Bethell et al., 2002a, 2002b). In summary, the order of administration of the two special-needs screening instruments did not have an effect on the proportion of children identified as having a special health care need by either set of questions.

More children were identified as having special health care needs with the QuICCC-R (23.6%) than with the CSHCN Screener (16.0%). Still, the agreement between the two screening instruments was very high, with 90% of the children classified similarly by both screeners. In 10% of the cases ($n = 237$), a child with special health care needs was identified by only one of the two screeners. The vast majority (89%) of these discrepant cases were identified as having special needs by just the QuICCC-R. Only 27 children (11%) were identified by the CSHCN Screener only. This result was not surprising given that the QuICCC-R includes several more items than the CSHCN Screener, offering more opportunities for a child to qualify as having a special health care need.

When parents were asked the open-ended question about the child's condition, children identified as having special health care needs by the QuICCC-R only were less likely to have a named chronic condition, compared to children who screened positively on both screeners. The children identified by the QuICCC-R only were also less likely to have a condition that parents reported as severe and were less likely to use health care services (Bethell et al., 2002a).

Another consideration in the selection of the screener was the length of time necessary to administer each. Longer screeners would cost more to administer. The mean household administration time for the CSHCN Screener was 2 minutes 6 seconds, compared with 3 minutes 55 seconds for the QuICCC-R. Given that agreement between the screeners was very high, the CSHCN Screener appeared to be a cost-effective screening tool.

Based on these results, a decision was made by the principal funding agency to adopt the CSHCN Screener for the National Survey of CSHCN. The CSHCN Screener questions, as presented in the National Survey of CSHCN, are listed in Table 2. Some readers may note that the order of the first two questions is different from the question order published in the research literature on the CSHCN Screener (Bethell et al., 2002b). For an explanation about why the order was changed for the National Survey of CSHCN, please see the results of the second pretest that are detailed in Appendix VII.

<< INSERT TABLE 2 ABOUT HERE >>

Questionnaire

The framework for the National Survey of CSHCN was initially discussed in August 1999. A panel consisting of state and federal Title V Program directors, representatives from

Table 2. CSHCN Screener questions, as used in the National Survey of CSHCN

Introductory Statements	
The following questions are about any kind of health problems, concerns, or conditions that may affect your child's behavior, learning, growth, or physical development. Some of these health problems may affect your child's abilities and activities at school or at play. Some of these problems affect the kind or amount of services your child may need or use.	
Stem Question	Follow-Up Questions
1. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?	(IF YES) Is your child's need for medical care, mental health or educational services because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
2. Does your child currently need or use medicine prescribed by a doctor, other than vitamins?	(IF YES) Is your child's need for prescription medicine because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?	(IF YES) Is your child's limitation in abilities because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
4. Does your child need or get special therapy, such as physical, occupational or speech therapy?	(IF YES) Is your child's need for special therapy because of any medical, behavioral, or other health condition? (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs treatment or counseling?	(IF YES) Has your child's emotional, developmental or behavioral problem lasted or is it expected to last 12 months or longer?
Note: For households with more than one child, the phrase "does your child..." was replaced with "do any of your children...." Affirmative answers were followed by a question asking for the names or ages of the children with that particular health care consequence. The follow-up questions were then asked separately for each named child.	

Table 2

Family Voices and the Association for Maternal and Child Health Programs, health services researchers, and survey design experts identified ten content domains of greatest epidemiological and policy importance (health and functional status; health insurance coverage; adequacy of health insurance coverage; public program participation; access to health care; health care utilization; care coordination; satisfaction with services; impact on the family; and demographics). A subset of this panel then assembled questions to capture these domains and recommended the screeners to be tested. (See table 3 for a list of panel members.)

<< INSERT TABLE 3 ABOUT HERE >>

Where possible, questions and batteries from existing surveys were used for the National Survey of CSHCN, to allow for comparisons with these surveys and to reduce the need for extensive pretesting. The surveys from which questions were drawn included the National Health Interview Survey (conducted by NCHS), the Consumer Assessment of Health Plans Survey (sponsored by the Agency for Healthcare Research and Quality), the Promoting Healthy Development Survey and the Living with Illness Survey (developed by the FACCT), the Questionnaire for Identifying Children with Chronic Conditions (Stein et al., 1997), Your Voice Counts (a survey developed by Family Voices and Brandeis University), and prior SLAITS modules.

Content

The National Survey of CSHCN questionnaire was designed to immediately follow a completed NIS interview in households with an NIS-eligible child, or the NIS screener in households without an NIS-eligible child. The questionnaire was divided into twelve sections, summarized below.

(1) Age-Eligibility Screening—This section consists of the introduction to the interview and the question to determine if any children under 18 years of age live in the household.

(2) Special Health Care Needs Screening—In this section, all of the children under 18 years old in the household were rostered, with gender, date of birth, race, and ethnicity gathered for each child. For sampled children, additional items included the relationship of the respondent to the sampled child(ren) and the educational level of the respondent or, in those cases where the respondent was not the mother of the sampled child(ren), the educational level of the mother and whether the mother resided in the household. The CSHCN Screener was also administered in this section.

(3) Health and Functional Status—This section included questions regarding the sampled child's physical, mental, behavioral, learning, and developmental conditions and the impact of these conditions on the child's life.

(4) Access to Care, Utilization, and Unmet Needs—The questions in this section addressed the availability of medical services for the sampled children and their families and the degree to which they used them. More specifically, respondents were asked about the types of medical services the child required in the last year; whether they had experienced any problems accessing

Table 3. Panel Members, August 1999

Name	Affiliation (in 1999)
Christina Bethell, PhD	Foundation for Accountability
Stephen Blumberg, PhD	National Center for Health Statistics, CDC
Treeby Brown, MA	Association of Maternal and Child Health Programs
Gil Buchanan, MD	Arkansas Department of Health
Marcie Cynamon, MA	National Center for Health Statistics, CDC
Trena Ezzati-Rice, MS	National Center for Health Statistics, CDC
Cathy Hess, MSW	Association of Maternal and Child Health Programs
Deborah Klein Walker, EdD	Massachusetts Department of Health
Cassie Lauver, ACSW	Kansas Department of Health and the Environment
Jeffrey Lobas, MD, MPA	Iowa Child Health Specialty Clinics
Jennifer Madans, PhD	National Center for Health Statistics, CDC
Stephanie McDaniel	Association of Maternal and Child Health Programs
Peggy McManus, MHS	MCH Policy Research Center
Merle McPherson, MD	Maternal and Child Health Bureau, HRSA
Kerry Nesseler, RN, MS	Maternal and Child Health Bureau, HRSA
Paul Newacheck, DrPH (chairperson)	University of California at San Francisco
Ruth Stein, MD	Yeshiva University
Bonnie Strickland, PhD	Maternal and Child Health Bureau, HRSA
Peter van Dyck, MD, MPH	Maternal and Child Health Bureau, HRSA
Gloria Weissman, PhD	Maternal and Child Health Bureau, HRSA
Nora Wells, MEd	Family Voices / Federation for Children with Special Needs

Table 3

medical care for the sampled child; and whether they had delayed medical treatment for the child and if so, the reasons for the delay.

(5) Care Coordination—In this section, the respondents were asked whether a professional (e.g., a case manager) helped coordinate care for the sampled child. If professional assistance was received, additional questions assessed the quality of this assistance.

(6) Satisfaction with Care—This section asked respondents about the medical care provided to the sampled child and the communication between the child’s doctor and the child’s parents or guardians.

(7) Health Insurance—The main goal of this section was to establish whether sampled children had comprehensive health insurance coverage. Comprehensive coverage was defined as insurance that pays for both doctor visits and hospital stays. The section included questions asking whether a sampled child was covered by any of a series of common types of medical insurance. Respondents with insured children were asked about any interruptions in the insurance coverage that might have occurred in the past. For the uninsured children, information was collected on how long it had been since they last had medical coverage.

(8) Adequacy of Health Care Coverage—Respondents with insured children were asked about adequacy of health coverage. They were asked to rate the cost and benefits of, and their satisfaction with, the insurance plans in which the children were enrolled.

(9) Impact on the Family—This section included questions regarding the impact that a child’s special health care needs have on the child’s family. It assessed financial and time burdens and the ways in which the families were coping with them.

(11) Income and Other Demographics—In this section, respondents were asked about their income, government program participation, number of telephone lines in their household, interruptions in their telephone service during the past year, and their zip codes. The annual household income was mapped to DHHS Federal Poverty Guidelines. This made it possible to categorize the household’s income relative to the poverty level.

(12) Medicaid and SCHIP Knowledge and Experience—The questions in this section, part of the Low-Income Uninsured Supplement, assessed the respondent’s level of knowledge about Medicaid and SCHIP programs in their state. The respondents were also asked how easy or difficult they believed it was to enroll in these programs and whether they had ever attempted to enroll the sampled child. Those who had not enrolled were asked their reasons for not doing so.

(13) Utilization and Barriers to Care Questions for Low-Income/Uninsured Children without Special Health Care Needs—In this section, part of the Low-Income Uninsured Supplement, respondents with children who had no special health care needs were asked questions regarding the health problems of these children, medical services that they used, and the impact on the families of any health problems these children might have.

The questionnaire did not include a section labeled “Section 10,” which was a label that had been reserved for use but was not needed.

All households with children received the questions in sections 1 and 2, above. The special-needs interview consisted of sections 3 through 9 and 11. The health insurance control sample interview consisted only of sections 7 and 11. The Low-Income Uninsured Supplement interview consisted of sections 12 and 13.

A copy of the questionnaire appears in Appendix II. Appendix III provides a listing of changes made in the questionnaire over the course of the study. Appendix IV contains the DHHS Federal Poverty Guidelines tables used to determine household poverty status during interview administration and a description of the process for assigning poverty status to households.

Computer-Assisted Telephone Interviewing

The National Survey of CSHCN was conducted using a computer-assisted telephone interview (CATI) system. The CATI data collection method employs computer software that presents the questionnaire on computer screens to each interviewer. The computer program guides the interviewer through the questionnaire, automatically routing the interviewer to appropriate questions based on answers to previous questions. Interviewers enter survey responses directly into the computer and the CATI program determines if the selected response is within an allowable range, checks it for consistency against other data collected during the interview, and saves the responses into a survey data file. On-line help facilities are available to aid interviewers in administering the CATI questionnaire. This data collection technology reduces the time required for transferring, processing, and releasing data, and it ensures the accurate flow of the questionnaire.

The National Survey of CSHCN questionnaire was programmed as a module of the NIS, integrating the two surveys into a single interview. The instrument made full use of the CATI system’s ability to check whether a response was within a legitimate range, to follow skip patterns, to fill state-specific information in questions as applicable (for example, names of state Medicaid and SCHIP programs), and to employ pick lists for response categories. Certain household and demographic questions were identical in the NIS and National Survey of CSHCN portions of the interview. If a respondent answered these questions during NIS administration, the system was programmed so that the questions were not repeated in the National Survey of CSHCN. Instead, the answers to these questions in the NIS were copied to the data file for the National Survey of CSHCN, as appropriate.

National Survey of CSHCN Stand-Alone Questionnaire

As noted earlier, the amount of sample required to reach the target number of completed special-needs interviews for the National Survey of CSHCN exceeded the NIS sample available in some IAP areas. For these IAP areas, additional National Survey of CSHCN-only sample was created. Respondents in this augmentation sample did not receive any questions from the NIS screener or interview. Rather, the CATI system was programmed to begin with the National Survey of CSHCN.

Pretests of the CATI Instrument

Once initial programming was completed, the instrument underwent rigorous testing to ensure correct functioning of the CATI system. In addition, two pretests were conducted. The first pretest (discussed previously) was designed primarily to test two different screening instruments developed to identify special health care needs in children. The second pretest (discussed in Appendix VII) was designed primarily to investigate the impact of different advance mailings and introductory scripts on NIS and National Survey of CSHCN response rates. In addition to their primary purposes, these pretests also suggested improvements that could be made to the CATI programming and to the questionnaire. The findings were incorporated into the final CATI instrument.

Interviewer Training

Abt Associates Incorporated and their subcontractors conducted all interviews for the National Survey of CSHCN. The initial data collection staff for the National Survey of CSHCN was recruited during October and November 2000. To offset interviewer attrition, interviewer recruitment and training continued throughout the duration of the study. Interviewer training was conducted by staff from Abt Associates in their telephone centers in Chicago, Illinois; Las Vegas, Nevada; and Amherst, Massachusetts. The use of several telephone centers made it possible to maintain the level of interviewer coverage needed to call such a large sample in multiple time zones. (Interviews were conducted from 9 a.m. to 9 p.m. in each of the six time zones covered by the 50 states.) The numbers of interviewers who completed training each month in each location are included in Table 4.

<< INSERT TABLE 4 ABOUT HERE >>

Training sessions for the pretests and the main survey began with an introduction to the study and its sponsors, the reasons for conducting the study, and other background information. This background included discussion on how the National Survey of CSHCN was conducted in conjunction with the NIS, the age-eligibility ranges for the two studies, the length of time required to conduct both surveys, and the procedures to be followed for gaining cooperation for each study. The main interviewer goals (e.g., the number of completed interviews, the expected time frame for data collection) were also discussed.

Mock interviews were conducted to acquaint interviewers with the questionnaire and to provide them with the project knowledge and refusal aversion skills necessary to conduct an interview. Two types of mock interviews were performed: trainer-led mocks in which the trainer carried out the role of the respondent and the interviewers conducted the interview using the CATI system, and dual mocks in which one trainee performed the role of the interviewer while the other acted as the respondent. Trainer-led mock interviews included discussions of the goals of each questionnaire section and of specific questions. Extra attention was given to specific questions in the screener and to specific sections on child health status, specialty care, care coordination, and health care coverage.

A final mock interview and written evaluation were administered at the end of the training session. The mock interview was standardized, thus allowing interviewers to be evaluated against the same standard on their ability to navigate through CATI, gain cooperation, and answer frequently asked questions from respondents. The written evaluation was

Table 4. Interviewers Trained by Month and Telephone Center Location

Month	Chicago (57.4%)	Las Vegas (28.0%)	Amherst (14.5%)	Total (100%)
October 2000	145	102	0	247
November 2000	43	29	26	98
December 2000	10	0	0	10
January 2001	55	16	0	71
February 2001	83	34	12	129
March 2001	34	29	11	74
April 2001	31	0	30	61
May 2001	32	20	19	71
June 2001	53	28	19	100
July 2001	49	11	24	84
August 2001	14	16	0	30
September 2001	26	21	0	47
October 2001	45	11	0	56
November 2001	34	10	11	55
December 2001	26	5	20	51
Total	680	332	172	1184

Table 4

administered with the purpose of reinforcing what was learned during the course of training. Each trainer was provided with a written evaluation answer guide to rate the proficiency level of the interviewer. Interviewers had to successfully complete both evaluations in order to collect data for the National Survey of CSHCN.

Data Collection

Telephone interviewing for the main study began on October 17, 2000. Data collection, completed on April 30, 2002, included a total of 196,888 screening interviews with households having children, 38,866 special-needs interviews, 176,296 health insurance control sample interviews, and 9,935 Low-Income Uninsured Supplement interviews. As noted earlier, each child eligible for the Low-Income Uninsured Supplement interview also was the subject of a completed special-needs interview or health insurance control sample interview. Thus, the total number of completed child-level interviews was 215,162 (that is, the sum of 38,866 and 176,296). These children were randomly selected from the 373,055 completed child-level screener interviews (see Figure 1). Table 5 details the total number of interviews completed by type and state.

<< INSERT FIGURE 1 AND TABLE 5 ABOUT HERE >>

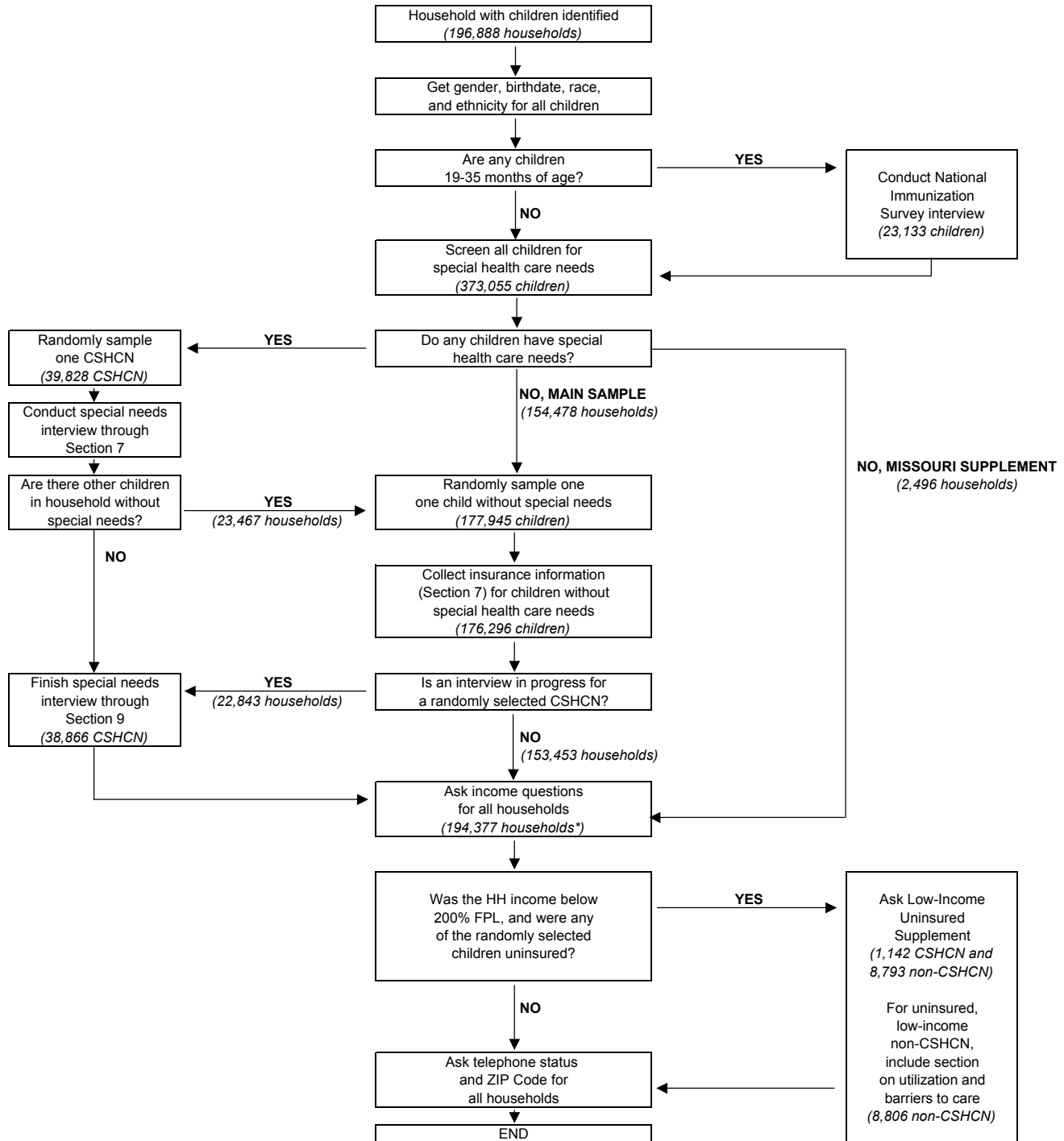
Not all states have exactly 750 completed special-needs interviews. The reason for this has to do with the nature of the sample. In each state, to reach the target of 750 interviews, the number of telephone lines dialed was based on estimates of the proportion that would reach age-eligible households, the proportion of these households that would have a child with special health care needs, and the proportion of these households that would be willing to complete an interview. In some states, data collection fell a few interviews short of the target; in some states, data collection exceeded the target. Adding or dropping telephone lines at the end of the data collection period (in order to more closely reach the target) was not recommended because biased estimates may result if some lines are called less frequently or over shorter periods of time than others. An average of seven calls were made to each telephone number to complete an interview; the median was three.

Advance Letter

Advance letters have been shown to decrease nonresponse by increasing study legitimacy (Camburn et al., 1995). An advance letter (Appendix V) was mailed to presumed households when a mailing address could be identified for sampled telephone numbers—40.0% of the telephone numbers randomly generated and 62.3% of the telephone numbers dialed by the interviewers. Recipients were asked to participate in a voluntary study on the immunization of their children and the types of health and related services that their children need and use. The letter advised recipients that their telephone numbers had been chosen randomly, and indicated that they might be called in the next few weeks. A toll-free telephone number was provided for those who wished to participate immediately or to learn more about the study.

As described earlier, for IAP areas requiring sample beyond that available through the NIS, additional sample was created. Households in the augmentation sample with an identified mailing address were mailed an advance letter different from that used for NIS sample

Figure 1. Sample Design Flowchart



*Of the 194,377 households reporting income, 21,725 were NIS-eligible so reported income as part of that interview. The remaining 172,652 NIS-ineligible households reported income during the NS-CSHCN interview

Table 5. Completed Interviews by State and Type

State	Number of Completed Interviews			Number of CSHCN Screening Interviews Completed	
	Special-Needs Interviews	Health Insurance Control Sample Interviews	Low-Income Uninsured Supplement Interviews	Households with Children	Children Under 18 Years of Age
Alabama	749	3,493	213	3,843	6,904
Alaska	746	4,034	208	4,333	8,567
Arizona	751	3,948	419	4,276	8,558
Arkansas	749	3,297	280	3,655	6,622
California	759	4,661	408	4,967	9,688
Colorado	744	3,818	306	4,129	7,893
Connecticut	742	3,148	60	3,469	6,426
Delaware	742	2,977	112	3,339	6,185
District of Columbia	748	3,641	181	4,048	7,422
Florida	750	3,744	352	4,135	7,583
Georgia	748	3,690	215	4,077	7,490
Hawaii	747	4,633	112	4,976	9,397
Idaho	745	3,774	307	4,049	8,387
Illinois	745	3,710	199	4,027	7,774
Indiana	747	3,221	113	3,553	6,760
Iowa	751	3,640	131	3,948	7,798
Kansas	748	3,036	169	3,400	6,555
Kentucky	745	3,015	164	3,412	6,054
Louisiana	749	2,847	273	3,235	5,966
Maine	742	2,808	139	3,124	5,650
Maryland	750	2,968	83	3,345	6,184
Massachusetts	744	3,084	53	3,434	6,430
Michigan	748	3,154	107	3,485	6,657
Minnesota	749	3,331	115	3,612	6,967
Mississippi	743	3,639	238	4,005	7,390
Missouri	1,493	3,142	97	6,742	12,834
Montana	742	3,676	355	4,006	7,670
Nebraska	747	3,461	120	3,777	7,458
Nevada	747	4,243	425	4,553	8,932
New Hampshire	750	2,976	113	3,320	6,151
New Jersey	744	3,766	205	4,107	7,537
New Mexico	751	3,836	298	4,170	8,124
New York	748	3,953	149	4,308	8,044
North Carolina	739	3,239	201	3,624	6,448
North Dakota	746	3,640	182	3,949	7,550
Ohio	766	3,239	108	3,597	6,855
Oklahoma	745	3,219	289	3,589	6,720
Oregon	745	3,316	226	3,650	6,920
Pennsylvania	748	3,525	137	3,874	7,334
Rhode Island	750	3,058	70	3,378	6,146
South Carolina	745	3,291	150	3,647	6,668
South Dakota	741	3,847	179	4,120	8,223
Tennessee	747	3,199	102	3,567	6,354
Texas	751	3,722	541	4,088	7,854
Utah	742	3,635	253	3,896	8,892
Vermont	748	2,989	49	3,312	6,076
Virginia	747	2,903	111	3,288	5,843
Washington	756	3,185	91	3,517	6,660
West Virginia	748	3,061	187	3,441	6,040
Wisconsin	750	3,333	81	3,642	6,959
Wyoming	749	3,531	259	3,850	7,456
Total	38,866	176,296	9,935	196,888	373,055

*Some Missouri numbers are larger than those seen in other states because of the Missouri Supplemental Sample described earlier in this report.

Table 5

households. This advance letter asked respondents to participate in a study regarding the types of health and related services that their children need and use. No mention was made of the NIS or of immunizations.

Toll-Free Telephone Number

A toll-free telephone number was provided in the advance letter and in answering machine messages. Potential respondents could use this number to alert the interviewers that there were no children in the study's age range living or staying in their household, to ask questions about the study, or to complete an interview. During the course of data collection, 22,957 calls were received on this line, 65.2% of which were from households calling to indicate that they did not have a child eligible for the study. A total of 4,815 respondents who called the toll-free telephone number had age-eligible children and completed an interview.

Informed Consent

Consent for study participation was obtained from National Survey of CSHCN respondents as soon as it was determined that their household contained an age-eligible child. Respondents were informed about the voluntary nature of the survey, the authorizing legislation, and confidentiality of data collected. In addition, the informed consent script provided information about the content of the survey and the expected duration. The informed consent process also ensured that the person most knowledgeable about the children's health had received the consent information and agreed to participate. The Institutional Review Boards at NCHS and Abt Associates Incorporated approved these procedures.

Assurance of Confidentiality

Participation in surveys conducted by NCHS is voluntary, and information collected on individuals is confidential. For the National Survey of CSHCN, assurance of confidentiality was provided to potential respondents as part of the informed consent procedures. In the CATI system, interviewers acknowledged that they read the following script to potential respondents:

Your answers will be kept strictly private, in accordance with the Public Health Service Act. I can provide you with the legal description if you like. It guarantees that any answers that identify you or your family will not be shared with anyone other than the agency doing this survey.

If a respondent requested the legal description, the interviewer read the following:

The Public Health Service Act is Volume 42 of the US Code, Section 242K. The collection of information in this survey is authorized by Section 306 of this Act. The confidentiality of your responses is assured by Section 308d of this Act.

Section 308d of the Public Health Service Act states that:

No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under section...306,...may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented (as determined under regulations of the Secretary) to its use for such other purpose and in the case of information obtained in the course of health statistical or epidemiological activities

under section ...306, such information may not be published or released in other form if the particular establishment or person supplying the information or described in it is identifiable unless such establishment or person has consented (as determined under regulations of the Secretary) to its publication or release in other form.

Strict procedures are used to prevent disclosure of confidential data in survey operations and data dissemination.

Selection of Sampled Children

All children under 18 years of age living or staying in selected households were screened for the presence of special health care needs, using the CSHCN Screener. In households where a single child screened positive for a special health care need, that child was, by default, the child selected for the detailed special-needs interview. If more than one child in the household screened positive, one such child was randomly selected for the detailed interview.

Children with a negative screen for special health care needs were eligible for the health insurance control sample interview. In households where a single child screened negative for a special health care need, that child was, by default, the child selected for the health insurance control sample interview. If more than one child in the household screened negative, one such child was randomly selected for the insurance interview.

If a household had children with and without special needs, both interviews were administered in that household. Thus, in households with children under 18, there were three possible sampling outcomes:

- One child selected for the special health care needs interview and no child selected for the health insurance control sample interview.
- One child selected for the health insurance control sample interview and no child selected for the special health care needs interview.
- One child selected for the special health care needs interview and one child selected for the health insurance control sample interview.

At most, two children were selected (i.e., sampled) for an interview in any given household.

Sampled children of either type who were uninsured and who resided in a household with an annual income below 200% of the DHHS Federal Poverty Guidelines received the Low-Income Uninsured Supplement interview. Households where respondents refused or were unable to provide income information were considered to be below 200% of the poverty level and therefore qualified for the Low-Income Uninsured Supplement if the selected child was also uninsured.

Selection of Respondent

The respondent for the National Survey of CSHCN was the parent or guardian in the household who was most knowledgeable about the children's health and health care. In the majority of households, the respondent was the child's mother or father (or female/male guardian). Table 6 provides further information regarding the relationship of respondents to the sampled children.

<< INSERT TABLE 6 ABOUT HERE >>

Table 6. Relationship of Respondent to Sampled Child

Relationship of Respondent to Sampled Child	Number	Percent
Mother or Female Guardian	169,854	78.9%
Father or Male Guardian	36,891	17.2%
Grandparent	5,087	2.4%
Other Relative/Friend	3,205	1.5%
Unknown	61	< 0.05%
Don't Know/Refused	64	< 0.05%
Total	215,162	100.0%

Table 6

In most households with multiple children, a single adult was the parent or guardian most knowledgeable about the health and health care of all children in the household. In some households, however, there was a different knowledgeable adult for each child. In such households, the objective was to complete the initial screening interview with the person who could provide the most information about all of the children in the household, even though that person may not have been the person most knowledgeable about each child.

However, once the initial screening was completed and if a child with special health care needs was in the household, the parent or guardian who was most knowledgeable regarding the health of that child was the designated respondent for the remainder of the questionnaire. Thus, if the screener respondent did not know as much about the child sampled for the special-needs interview as did another adult in the household, the interview was conducted with the more knowledgeable respondent.

A parent, guardian, or other adult greater than 17 years of age was not identified in 198 households. No interviews were conducted in these households, even if an emancipated minor living there was also the parent of a younger child.

Interviewing in Spanish

The National Survey of CSHCN was designed to produce estimates of the number of CSHCN and the impact of those needs. Because excluding the age-eligible households with children where an interview could not be conducted in English would have resulted in a biased sample, it was important to develop methods to include these households. Interviewing in Spanish was conducted in the telephone centers, while data collection in ten additional languages was completed by field staff. This section details the procedures for Spanish interviewing. The next section details the procedures for other languages.

The Spanish-language version of the National Survey of CSHCN questionnaire was produced by first translating the completed English questionnaire into Spanish and then translating it back into English. The two components of this process were completed by independent contractors. At the conclusion of translation, discrepancies were resolved in consultation with the contractors and the resulting translation was incorporated into the CATI instrument. A final review was then conducted by a team of experienced Spanish-language telephone interviewers and supervisors, who evaluated the translation for accuracy and cultural appropriateness. Issues raised during this final review were resolved in consultation with the original translators, and the CATI instrument was finalized.

For data collection and sample management purposes, a calling queue was used for households thought by interviewers to be Spanish-speaking. A CATI flag indicated such households. An appointment was set for National Survey of CSHCN cases with the Spanish-language flag and they were then delivered, via the CATI system, to bilingual interviewers who were specially trained to conduct interviews in both Spanish and English. A total of 9,604 households with children in the Spanish-language queue were screened, resulting in the completion of 807 Spanish-language special-needs interviews, 9,266 health insurance control sample interviews, and 2,700 Low-Income Uninsured Supplement interviews. These cases account for 4.9% of all screened households, 2.1% of all special-needs interviews, 5.3% of all health insurance control sample interviews, and 27.2% of all Low-Income Uninsured Supplement interviews.

Interviewing in Languages other than English or Spanish

To determine which languages other than English or Spanish were most likely to be encountered during survey administration, data from the NIS were used to estimate the expected number of households with children, by language. These data revealed that 90% of such households spoke one of ten languages: Korean, Vietnamese, Mandarin, Japanese, Russian, Cantonese, Polish, French, Tagalog (the language of the Philippines), and Italian.

An independent contractor, Asian Translations, translated the National Survey of CSHCN questionnaire into each of the ten identified languages. Translated questionnaires were individually reviewed by a second professional translation company (Pacolet International) and by Abt Associates staff fluent in the respective language. Each questionnaire was then thoroughly reviewed by the field interviewers to ensure the cultural appropriateness of the questionnaire text. Any discrepancies between the original translations and the reviewers' comments were resolved in consultation with Asian Translations.

To identify which cases were eligible for interviewing in the ten languages, English-speaking telephone interviewers first identified cases in which respondents spoke neither English nor Spanish. These cases were then forwarded to specialized interviewers within the telephone center who conducted a preliminary screening for NIS-eligible children with the assistance of an AT&T Language Line interpreter. If this screening identified a child between the ages of 19 and 35 months, an NIS interview was administered using the interpreter. If no children between 19 and 35 months of age were identified, the interviewer immediately screened for the presence of other children under the age of 18 in the household. Once this age screening (and the NIS interview, if applicable) was completed, the interview terminated. For households with children under the age of 18 identified during this process, interviewers were asked to indicate the language spoken by the respondent. If the language indicated was one of the ten selected for National Survey of CSHCN interviewing, the case was removed from the CATI system for delivery to trained field interviewers. Field staff then contacted these cases to complete special-needs screening and all applicable interviews, via a hard-copy instrument.

Queue building for the National Survey of CSHCN began on October 17, 2000. To ensure a sufficient workload for other-language interviewers, cases were allowed to accrue for several months prior to interviewer recruitment and training. The first cases were released to bilingual field interviewers on March 8, 2001.

Of the 1,383 households with children identified and called by other-language interviewers, 1,311 (94.8%) were screened for the presence of special health care needs. Of those screened households, 1,281 (97.1%) completed a detailed special-needs interview or health insurance control sample interview, as applicable. A total of 1,263 health insurance control sample interviews, 48 special-needs interviews, and 117 Low-Income Uninsured Supplement interviews were completed. These other-language cases account for 0.7% of all screened households, 0.1% of all special-needs interviews, 0.7% of all health insurance control sample interviews, and 1.2% of all Low-Income Uninsured Supplement interviews. A summary of interviews completed, by language, appears in Table 7.

<< INSERT TABLE 7 ABOUT HERE >>

Table 7. Number of Interviews Completed, by Language

Language	Special Needs Interview	Health Insurance Control Sample Interview	Low-Income Uninsured Supplement Interview	Number of Screened Households
English	38,011	165,767	7,118	185,973
Spanish	807	9,266	2,700	9,604
Vietnamese	3	249	6	252
Cantonese	4	178	13	182
Mandarin	1	175	17	176
Korean	1	163	32	164
Russian	23	127	14	150
Tagalog	6	135	11	141
French	1	105	18	106
Japanese	4	78	2	82
Polish	5	49	4	54
Italian	0	4	0	4
Total	38,866	176,296	9,935	196,888

Table 7

Interview Length

The length of the full household interview varied considerably by the special-needs status of the children in the household, the number of children sampled, and the insurance and poverty status of the sampled children. Mean and median interview lengths were therefore calculated by household and interview type. These times also varied by NIS eligibility, because some demographic and household questions necessary for both the NIS and the National Survey of CSHCN were already administered as part of the NIS interview. These questions were not repeated during the National Survey of CSHCN interview.

The mean and median interview lengths by household type and by NIS eligibility are presented in Table 8. The mean and median interview lengths by type of interview, by NIS eligibility, and by section are presented in Table 9. Interview times shown for NIS-eligible households exclude administration time for the NIS interview itself.

<< INSERT TABLES 8 AND 9 ABOUT HERE >>

Interview Breakoffs

In households where an interview was begun but not completed, specially trained interviewers attempted to convert the incomplete interview into a completed interview. By the end of the data collection period, 11,026 interviews were completed with households that had originally refused to participate (5.7% of completed interviews). However, conversion was not successful with 58,588 identified households with children (2.2% of the total sample). The majority of these households (56,190) broke off the interview before completing the special-needs screening and before eligibility could be determined. Of these 56,190 households, 3,203 broke off during administration of the NIS interview, which preceded the National Survey of CSHCN interview.

For the remaining 52,987 households that progressed past the NIS screener or interview but ended the interview before special-needs screening was completed, the most common point for ending the interview was at the initial introduction to the National Survey of CSHCN interview. This introductory script included an overview of topics that would be covered during the interview and details regarding informed consent, and was read in both NIS-eligible and NIS-ineligible households. NIS-eligible households were somewhat more likely to end the interview at this point (49.2% of breakoffs in NIS-eligible households, compared with 45.2% of breakoffs in NIS-ineligible households). NIS-eligible households had already spent time completing the NIS interview, and these respondents may have been reacting to the stated estimate of the length of the National Survey of CSHCN included in this introduction. Because these households had young children, these incomplete interviews may also have been related to the demands of taking care of such children. Another common point for ending the interview prior to screener completion was at the question that asked for the dates of birth for all of the children in the household. NIS-eligible households were also more likely than NIS-ineligible households to end the interview at this point (35.5% of breakoffs in NIS-eligible households, compared with 15.6% of breakoffs in NIS-ineligible households). A third common location for ending the interview prior to special-needs screener completion was the item that asked for the parent or guardian in the household who was most knowledgeable regarding the health of the children. NIS-ineligible households were more likely to break off at this point (32.7% of breakoffs in NIS-ineligible households, compared with only 6.5% of breakoffs in NIS-eligible households). This is likely

Table 8. Average length of National Survey of CSHCN interview in minutes and seconds, by household type and National Immunization Survey eligibility*

Type of Household	NIS-Eligible		NIS-Ineligible	
	Mean	Median	Mean	Median
Households in which only a child with special needs was sampled	18:54	16:02	23:26	20:34
Households in which only a child without special needs was sampled	6:21	4:10	8:55	7:13
Households in which both a child with and a child without special needs were sampled	22:37	18:50	25:42	22:34

*NIS eligibility refers to household eligibility. NIS eligible households include at least one child between 19 and 35 months of age. The NIS-eligible child in the household may or may not have been the child sampled for the National Survey of CSHCN interview.

Table 9. Average length of National Survey of CSHCN interview in minutes and seconds, by interview type, by section, and by National Immunization Survey eligibility*

Type and Section of NS-CSHCN Interview	NIS-Eligible		NIS-Ineligible	
	Mean	Median	Mean	Median
SPECIAL-NEEDS INTERVIEW				
Overall Length	18:59	17:31	23:36	22:13
Section 1: Age-Eligibility Screening	1:06	0:45	2:05	1:25
Section 2: Special Health Care Needs Screening	2:34	1:46	3:28	3:03
Section 3: Health and Functional Status	1:34	1:24	1:55	1:44
Section 4: Access to Care - Utilization and Unmet Need	4:21	4:01	4:58	4:26
Section 5: Care Coordination	0:45	0:33	0:47	0:35
Section 6: Satisfaction with Care	1:59	1:52	2:07	1:56
Section 7: Health Insurance	1:29	1:14	1:29	1:19
Section 8: Adequacy of Health Care Coverage	1:41	1:31	1:47	1:38
Section 9: Impact on the Family	2:17	2:09	2:21	2:10
Section 11: Income and other Demographics	1:30	0:58	2:43	2:24
HEALTH INSURANCE CONTROL SAMPLE INTERVIEW				
Overall Length	6:39	4:57	8:48	7:56
Section 1: Age-Eligibility Screening	1:19	0:46	2:03	1:23
Section 2: Special Health Care Needs Screening	2:17	1:24	2:46	2:25
Section 7: Health Insurance	1:22	1:13	1:25	1:16
Section 11: Income and other Demographics	1:25	0:54	2:29	2:14
LOW-INCOME UNINSURED SUPPLEMENT				
Overall Length	7:00	6:31	7:23	6:59
Section 12: Medicaid and SCHIP Knowledge/Experience	3:03	2:53	3:01	2:49
Section 13: Utilization and Barriers to Care Questions	3:58	3:37	4:21	4:05

*NIS eligibility refers to household eligibility. NIS eligible households include at least one child between 19 and 35 months of age. The NIS-eligible child in the household may or may not have been the child sampled for the National Survey of CSHCN interview.

because the preferred National Survey of CSHCN respondent and the NIS respondent were typically the same person, meaning that the correct respondent was already engaged with the interviewer.

Among cases that prematurely ended the interview after special-needs screening was completed and a child was sampled ($n = 2,398$, 0.1% of the total sample), there was little commonality in the location where the interview was terminated.

Cases Pending at the Close of Data Collection

Most of the cases pending at the end of the data collection period were those in which the telephone number had not yet been resolved as residential or nonresidential (75.9% of the pending cases and 12.6% of the initial sample). A smaller number of cases had been resolved as households without respondent eligibility being determined, and an even smaller number of households with an eligible respondent did not complete the interview (3.8% and 0.1% of the initial sample, respectively).

Response Rates

Response rates provide one measure of the potential for nonresponse bias—that is, the possibility that the sample interviewed differs from the actual population in some meaningful way. Three separate weighted response rates were calculated for the National Survey of CSHCN, to reflect the potential for nonresponse bias in 1) the sample of children screened for special needs, 2) the sample of CSHCN for whom the special-needs interview was completed, and 3) the sample of children for whom health insurance data were collected. These response rates, based on the Council of American Survey Research Organizations (CASRO) guidelines, were calculated in accordance with the American Association for Public Opinion Research's *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for RDD Telephone Surveys and In-Person Household Surveys* (American Association for Public Opinion Research, 2000) and using the assumptions for Response Rate #3 detailed by Ezzati-Rice et al. (2000b).

Response rates for telephone surveys are typically lower than response rates for household in-person surveys because some telephone numbers ring with no indication of whether the number belongs to a household or to a business. The national resolution rate, which measures the proportion of sampled telephone numbers that could be identified as residential or non-residential, was 86.5% for the National Survey of CSHCN. When called, the majority of the unresolved telephone numbers rang with no answer. (Most of the remaining unresolved numbers either reached persons or machines who “hung up” before identifying themselves or reached answering machines that provided no indication whether the caller reached a residence or a business.) This resolution rate is one component of the three overall response rates.

Special-Needs Screener Response Rate— Screening for the National Survey of CSHCN took place in two stages—initial age-eligibility screening in all households, followed by special-needs screening in households with at least one child less than 18 years of age. The national household completion rate for the initial age-eligibility screener was 94.9%, with 76.2% of age-eligible households completing the special-needs screener.

When possible, all children in each age-eligible household with children were screened for special needs. A child-level special-needs screener completion rate can be calculated that

measures the proportion of children screened from all households identified with age-eligible children. The total number of children in NIS-ineligible households was established at the time of initial age screening. However, in NIS-eligible households, the total number of children less than 18 years of age in such households was not determined until later, within the NIS interview itself. In 79 NIS-eligible households, the NIS interview was not completed to this point and thus the NIS question regarding number of children in the household was not asked. These households were known to be age-eligible, but the number of children in each household was not known. Therefore, in order to calculate the child-level special-needs screener completion rate, the total number of children less than 18 years of age (for these 79 households) was imputed as the average number of children in NIS-eligible households that did complete the NIS question regarding number of children.

The child-level special-needs screener completion rate was 77.2%. The weighted CASRO special-needs screener response rate was then calculated as the product of the household-level resolution rate (86.5%), the household-level age-screener completion rate (94.9%), and the child-level special-needs screener completion rate (77.2%). This national response rate was 63.4%. Weighted state special-needs screener response rates ranged from 55.0% in New Jersey to 74.2% in South Dakota. (See Table 10.)

<< INSERT TABLE 10 ABOUT HERE >>

Special-Needs Interview Response Rates—The special-needs interview response rate looks at the potential for nonresponse bias among estimates derived from the special-needs interview. It is necessarily lower than the special-needs screener response rate, because additional bias is possible if special-needs interviews were not completed in all screened households with CSHCN. The child-level special-needs interview completion rate, which measures the proportion of interviews completed among screened, eligible, and sampled children was 97.6%.

The weighted CASRO special-needs interview response rate was calculated as the product of the household-level resolution rate (86.5%), the household-level age-screener completion rate (94.9%), a household-level special-needs screener completion rate, and the child-level special-needs interview completion rate (97.6%). Because the unit of analysis for the detailed special-needs interview was the sampled special-needs child, the calculation of this response rate uses a household-level rather than a child-level special-needs screener completion rate. This completion rate, which measures the proportion of age-eligible households in which special-needs screening was completed, was 76.2% (as indicated earlier). Thus, the national special-needs interview response rate was 61.0%. Weighted state special-needs interview response rates ranged from 53.3% in New Jersey to 72.0% in Montana.

Health Insurance Interview Response Rates—With the inclusion of the health insurance control sample for children with special health care needs, health insurance data were collected for children regardless of their special-needs status. The health insurance interview response rate provides one measure of the potential for nonresponse bias among estimates derived from these data. The weighted CASRO health insurance interview response rate was calculated as the product of the household-level resolution rate (86.5%), the household-level age-screener completion rate (94.9%), the household-level special-needs screener completion rate (76.2%), and a child-level health insurance interview completion rate. This latter completion rate, which measures the proportion of eligible sampled children (regardless of special-needs status) for

Table 10. Weighted Response Rates, Nationally and by State

State	Household-Level Completion Rates			Child-Level Completion Rates			Overall CASRO Response Rates		
	Household-Level Resolution Rate	Age Screener	Special-Needs Screener	Special-Needs Screener	Special-Needs Interview	Health Insurance Interview ¹	Special-Needs Screener ²	Special-Needs Interview ³	Health Insurance Interview ⁴
National	86.5%	94.9%	76.2%	77.2%	97.6%	98.8%	63.4%	61.0%	61.8%
Alabama	87.9	95.4	76.6	77.6	98.3	98.8	65.0	63.2	63.5
Alaska	88.9	95.3	82.8	82.7	98.2	99.3	70.1	68.9	69.7
Arizona	86.8	95.2	76.5	77.5	97.0	98.6	64.0	61.3	62.3
Arkansas	90.8	96.5	78.8	80.1	97.5	98.8	70.1	67.3	68.2
California	85.3	94.1	74.6	75.4	97.9	99.2	60.5	58.6	59.4
Colorado	86.4	95.7	79.0	80.0	97.5	99.1	66.1	63.6	64.7
Connecticut	84.6	94.5	76.1	77.3	97.4	98.7	61.8	59.2	60.0
Delaware	82.2	94.6	75.9	77.2	96.1	98.3	60.0	56.7	58.0
D. C.	82.8	95.0	76.8	77.8	96.3	98.3	61.2	58.2	59.4
Florida	84.6	94.5	74.2	75.2	97.3	98.4	60.1	57.8	58.4
Georgia	87.4	95.1	76.0	77.3	96.3	98.5	64.3	60.8	62.2
Hawaii	90.3	92.2	72.6	73.0	97.8	99.0	60.8	59.1	59.8
Idaho	90.1	96.2	82.6	83.4	98.4	99.0	72.3	70.5	70.9
Illinois	86.5	95.0	75.5	76.7	97.4	98.6	63.1	60.5	61.2
Indiana	88.2	95.3	74.9	76.1	97.7	98.8	64.0	61.6	62.3
Iowa	90.9	95.9	79.2	80.8	97.4	98.7	70.4	67.2	68.1
Kansas	89.0	96.0	78.9	79.6	97.3	98.7	68.0	65.6	66.5
Kentucky	89.7	95.9	75.1	75.6	97.9	99.0	65.0	63.2	63.9
Louisiana	89.4	94.4	73.7	74.1	97.0	98.1	62.5	60.3	61.1
Maine	89.2	96.5	80.3	81.1	98.3	99.2	69.8	67.9	68.5
Maryland	84.0	94.2	76.2	77.3	97.3	98.3	61.2	58.7	59.3
Massachusetts	83.7	95.1	76.0	77.2	97.9	98.8	61.4	59.2	59.7
Michigan	86.6	95.1	76.8	77.3	97.8	98.8	63.7	61.9	62.5
Minnesota	90.1	95.6	79.1	79.9	99.1	99.4	68.8	67.5	67.7
Mississippi	88.7	94.9	75.7	76.9	95.9	98.2	64.7	61.1	62.6
Missouri	88.3	94.0	76.9	77.7	97.3	98.6	64.5	62.1	62.9
Montana	91.2	97.1	82.2	82.6	98.9	99.3	73.1	72.0	72.2
Nebraska	91.5	96.0	80.1	81.4	97.5	99.0	71.5	68.6	69.6
Nevada	84.0	94.4	76.3	77.6	97.9	99.0	61.5	59.2	59.8
New Hampshire	85.7	95.6	78.1	79.1	98.0	99.0	64.8	62.7	63.3
New Jersey	78.9	93.5	74.1	74.6	97.6	98.9	55.0	53.3	54.0
New Mexico	89.8	95.4	79.8	81.1	97.2	98.8	69.4	66.4	67.5
New York	83.9	94.4	73.9	74.5	97.0	98.5	59.0	56.8	57.6
North Carolina	87.5	95.7	76.8	77.8	98.0	98.7	65.2	63.1	63.5
North Dakota	91.4	96.7	81.8	83.2	98.3	99.1	73.5	71.1	71.7
Ohio	89.2	95.5	76.5	77.1	98.0	98.9	65.7	63.9	64.4
Oklahoma	88.9	95.2	76.9	78.0	97.6	98.6	66.0	63.5	64.1
Oregon	89.3	96.0	79.8	80.4	98.0	99.0	68.9	67.0	67.7
Pennsylvania	84.8	95.9	76.0	77.5	96.8	98.4	63.0	59.8	60.8
Rhode Island	86.5	95.3	77.2	77.6	97.9	98.9	63.9	62.3	62.9
South Carolina	87.9	95.3	75.9	77.3	97.8	98.9	64.8	62.2	63.0
South Dakota	92.6	96.9	81.4	82.7	97.6	98.9	74.2	71.3	72.3
Tennessee	87.4	95.1	75.0	76.2	97.9	98.9	63.4	61.1	61.7
Texas	87.3	94.1	75.5	76.8	97.4	98.5	63.1	60.4	61.0
Utah	89.0	95.4	79.8	81.3	97.1	98.7	69.0	65.8	66.9
Vermont	90.2	96.5	82.0	83.0	98.2	99.1	72.3	70.1	70.7
Virginia	85.6	94.7	77.4	78.6	97.3	98.7	63.7	61.1	62.0
Washington	88.1	95.0	79.1	79.9	98.4	99.2	66.9	65.1	65.7
West Virginia	88.3	96.2	77.7	79.1	97.8	98.9	67.2	64.5	65.3
Wisconsin	88.0	96.4	79.2	80.2	98.6	99.3	68.0	66.3	66.7
Wyoming	91.1	96.6	82.5	83.5	97.7	99.1	73.5	70.9	72.0

¹Depending on a child's special-needs status, the health insurance questions were asked as part of either the special-needs interview or the health insurance control sample interview. The health insurance interview completion rate is calculated for all sampled children, regardless of special-needs status.

²Special-needs screener response rate is the product of the household-level resolution rate, the household-level age-screener completion rate, and the child-level special-needs screener completion rate.

³Special-needs interview response rate is the product of the household-level resolution rate, the household-level age-screener completion rate, the household-level special-needs screener completion rate, and the child-level special-needs interview completion rate.

⁴Health insurance interview response rate is the product of the household-level resolution rate, the household-level age-screener completion rate, the household-level special-needs screener completion rate, and the child-level health insurance interview completion rate.

Table 10

whom health insurance data were collected, was 98.8%. Thus, the national health insurance interview response rate was 61.8%. Weighted state health insurance interview response rates ranged from 54.0% in New Jersey to 72.3% in Montana.

The final disposition of the sampled telephone numbers is summarized in Table 11. More detailed information regarding final sample disposition and national unweighted household response rate calculations appears in Appendix VI.

<< INSERT TABLE 11 ABOUT HERE >>

Efforts to Maximize Response Rates

As detailed earlier, a number of approaches were used to maximize response rates for the National Survey of CSHCN. To summarize, these approaches included:

- Careful attention to the introductory questionnaire script to ensure that it engaged the interest of potential respondents and provided clear information regarding the study sponsor
- An advance mailing to households having directory-listed telephone numbers to establish the legitimacy of the study and increase rapport prior to the first contact
- Thorough pretesting of the survey instrument to ensure that it was clear to respondents and not unduly burdensome
- A toll-free telephone number to allow respondents to contact Abt staff, encouraging potential respondents to obtain information about the study, immediately establish study eligibility, and voice any concerns
- A Spanish-language version of the survey instrument to reduce nonresponse bias among Spanish-speaking households
- Implementation of an other-language interviewing component, in which the questionnaire was translated into ten languages other than English and Spanish, and administered by specially trained interviewers fluent in these languages
- A sample management plan that ensured that the correct number of cases were in the field at any given time, and provided daily review of appointment and refusal case status to ensure timely recontact
- An interviewer training program in refusal aversion to reduce the number of unresolved cases and refusals from eligible respondents
- Refusal conversion attempts by specially trained interviewers, who prepared case-specific strategies for each conversion call based on call history

The first two strategies received special attention during a second pretest of the survey. This pretest was designed to investigate a full range of advance mailing and introductory script alternatives, in an effort to increase NIS and National Survey of CSHCN response rates. Details regarding the second pretest appear in Appendix VII.

Table 11. Final disposition of the National Survey of CSHCN sample

Final Disposition	Number of Selected Telephone Lines	Percent of Total Telephone Lines Selected
Not Resolved as Residential/Nonresidential	329,205	12.6%
Out of Scope (i.e., Business, Nonworking, Fax/Modem)	1,371,845	52.4%
Known Household, Age Eligibility not Determined	43,972	1.7%
Age-Screened Household, No Child in Age Range	621,122	23.7%
Known Age-Eligible Household, Special Needs Eligibility not Determined	57,453	2.2%
Special Needs Eligibility Determined, No Child Sampled*	2,496	0.1%
Screened Eligible Household, Interview Not Completed	2,070	0.1%
Screened Eligible Household, Partially Completed Interview	328	< 0.05%
Completed Interview	191,993	7.3%
Total	2,620,484	100.0%

* In the Missouri Supplemental Sample, children were not sampled for the health insurance control sample interview.

Quality Control

To ensure high quality data, program staff continually monitored the interviewers, the sample selection procedures, the consistency of the data, and the estimation procedures.

Quality Control of Interviewing

Telephone Center supervisors were available to interviewing staff at all times to resolve any questions or concerns about a case. Supervisors regularly observed the data collection process to informally monitor interviewers. In addition, supervisory staff used remote telephone and computer monitoring technology to evaluate whether the interviewers performed according to project specifications. This formal monitoring was conducted to see that introductory materials were properly read, that item wording and sequence of the questionnaire were followed correctly, that respondent questions were answered properly, and that any vague responses were properly probed. Computer monitoring also allowed supervisors to ascertain whether answers were entered accurately into the CATI system.

Supervisory staff monitored 5% of all calls made for the National Survey of CSHCN. Selection of interviewers for monitoring was automated using an algorithm that ensured that newly trained interviewers were monitored more often than experienced interviewers. Experienced interviewers were prioritized for monitoring based upon the length of time since their last monitoring session and recent monitoring scores. Each interviewer was typically monitored at least once a week; however, some interviewers were monitored more often.

Sample Monitoring and Quality Control

The prepared sample of telephone numbers was checked to ensure that it met the sample design specifications. The sample was monitored on a daily basis to ensure that the pace of data collection was consistent across the data collection period, and to prevent the unnecessary release to the telephone centers of excess cases. Daily analyses of the dynamics in the sample were produced to assist in timely sample management decision-making.

Data Quality Control

The CATI system was programmed to help ensure complete and accurate data collection, using automated data checking techniques, such as response-value range checks and consistency edits, during the interview process. These features enabled interviewers to obtain needed clarifications while still on the telephone with the respondent. Throughout data collection, interview data were reviewed for consistency between fields, appropriate response-value ranges, skip logic patterns, and missing information.

Procedures for Developing Sampling Weights

This section provides a nontechnical overview of the weighting procedures for the National Survey of CSHCN; for a more detailed and technical description, refer to Appendix I.

Household Screener Weight

A household weight was generated for analysis of households that completed a screener interview. For example, analysis of the proportion of households with CSHCN would use the household screener weight. This weight is composed of a base sampling weight, an adjustment for multiple telephone lines, and adjustments for household-level nonresponse. The final, adjusted weight is poststratified so that the sum of the household weights for each state matches the number of households with children as projected from the 2000 Census.

Base Sampling Weight—The goal of the National Survey of CSHCN was to complete at least 750 interviews for CSHCN in each state over the course of 18 months. First, the total number of telephone lines required to obtain this number of completes was estimated. Then, enough NIS sample to obtain the requisite number of completed cases for the National Survey of CSHCN for each quarter was selected. Some IAP-area samples contained too few telephone numbers to obtain the desired number of completed cases. In these areas, additional telephone numbers (i.e., augmentation sample) were randomly selected to reach the National Survey of CSHCN targets.

The telephone lines selected to be screened for the National Survey of CSHCN represent a random sample of all possible telephone lines in each geographic area. The probability that any given telephone line will be selected from the population of all possible telephone lines can be calculated:

If there were 1,000 total telephone lines in a given area, and 100 of those lines were selected for the study, the probability that any single telephone line would be selected is $100/1000$, or .10.

Each telephone line selected for the National Survey of CSHCN represents some larger number of telephone lines in the geographic area. This number can be calculated as the inverse of the probability of selection for any single telephone line:

If the probability of selection for any single telephone line was .10, then each telephone line selected represents $1/.10$, or 10, telephone lines in the geographic area.

This number—the inverse of the probability of selection for any single telephone line—is the base sampling weight, and was attached to each completed household interview in that geographic area. The base sampling weights vary by geographic area, but were the same for every completed interview within that geographic area. Because the population of telephone numbers did not change much by quarter, the base sampling weight was calculated for the overall survey and not separately for each quarter.

Adjustment for Households with Multiple Telephone Lines—If a household has multiple voice-use telephone lines, this household has a greater chance of being included in the survey than does a household with only a single voice-use telephone line.

Because the National Survey of CSHCN is a survey of households, and of children in those households, each household in a given state should have an equal probability of being in the sample. To adjust for the increased probability of households with multiple telephone lines being included in the sample, the base sampling weight is divided by the number of voice-use telephone lines in the household:

If a household had two voice-use telephone lines, this household could be included in the sample two times. If it was included twice, the household would represent 10 (base sampling weight) $\times 2$ (number of telephone lines) = 20 households. To adjust the weight so that the multiple-line household in the sample represents the same number of

households in the geographic area as does a single-line household in the sample, the base sampling weight (10) is divided by the number of telephone lines (2). With an adjusted weight of 5, this household (had it been selected twice) would still represent only 10 households.

First Form of Nonresponse: Unknown Household Status—When the selected telephone lines are called, three results are possible:

- It is determined that the telephone line belongs to a household.
- It is determined that the telephone line is not a working residential number, but rather is a business number or is nonworking.
- The status is undetermined because the telephone rings without an answer, the person answering the telephone hangs up immediately, or the telephone-answering device does not indicate whether the telephone line belongs to a household.

This third category includes some household telephone lines, but the exact number of household telephone lines in this category is unknown. Still, the completed household interviews must represent the households in this "unknown" category. When the number of households in the unknown category is large, the weight for each completed household interview must be increased a great deal. When the number of households in the unknown category is small, the weight for each completed household interview must be increased only slightly. This proportional adjustment is the first unit nonresponse adjustment.

The size of the adjustment is based on the size of the "unknown" category after all telephone numbers have been called several times, and is based on previous research in which telephone company business offices reported on the number of households among the "unknown" numbers. This adjustment varies based on geographic area, telephone area code, and whether the telephone line was directory-listed. When many telephone numbers in a geographic area and area code go unanswered, and most of these numbers are highly likely to be households, the weights for completed interviews in that geographic area and area code are increased greatly. When few telephone numbers in a geographic area and area code go unanswered, or few of these numbers are likely to be households, the weights for completed interviews in that geographic area and area code are increased only slightly.

In other words, based on the frequency of the nonresponse in a given area, compensation is made for this nonresponse by proportionately increasing the weights for those interviews that could be completed in that area. The completed interviews, therefore, represent the households in the "unknown" category.

Second Form of Nonresponse: Unknown Household Eligibility—When a household has been identified, three results are possible:

- It is determined that the household includes an age-eligible child and is therefore eligible for further screening.
- It is determined that the household does not include a child and is therefore not eligible.
- The screening interview is not completed, and the eligibility of the household is unknown.

This third category includes some age-eligible households. The exact number of age-eligible households in this category is unknown. Still, the completed household interviews must represent the age-eligible households in this "unknown" category. When the number of age-eligible households in the unknown category is large, the weight for each completed household interview must be increased a great deal. When the number of age-eligible households in the

unknown category is small, the weight for each completed household interview must be increased only a little bit. This proportional adjustment is the second unit nonresponse adjustment.

The size of the adjustment is based on the size of the first two categories. That is, the proportion of age-eligible households in the unknown category is assumed to be the same as the proportion of age-eligible households among all households where the screening interview for the presence of children was completed. This adjustment varies based on geographic area. When the age-eligibility for many households in a geographic area is unknown, and a high proportion of the completed eligibility interviews in that area revealed age-eligible children, the weights for completed interviews in that geographic area and sample are increased greatly. When the age-eligibility for only a few households in a geographic area and sample is unknown, or few of the completed eligibility interviews in that area revealed age-eligible children, the weights for completed interviews in that geographic area and sample are increased only slightly.

In other words, based on the frequency of nonresponse to the age-eligible screening interview in a given area and in a given sample, compensation is made for this nonresponse by proportionately increasing the weights for those interviews that could be completed in that area. The completed interviews, therefore, represent the age-eligible households in the "unknown" category.

Third Form of Nonresponse: Eligible Households Who Do Not Complete the Screener—When an age-eligible household has been identified, two results are possible for the household:

- The CSHCN Screener is completed.
- The CSHCN Screener is not completed.

The completed household screeners must represent the households in this "incomplete" category. When the number of incomplete screeners is large, the weight for each completed household screener must be increased a great deal. When the number of incomplete screeners is small, the weight for each completed household screener must be increased only slightly. This proportional adjustment is the third unit nonresponse adjustment.

The size of the adjustment is based on the size of the two categories, and is calculated simply as the ratio of the total number of age-eligible households to the number of completed screener interviews. This adjustment varies based on geographic area.

In other words, based on the frequency of nonresponse among age-eligible households in a given area and in a given sample, this nonresponse is compensated for by proportionately increasing the weights for those screeners that could be completed in that area. The completed screeners, therefore, represent the age-eligible households with incomplete screeners.

Poststratification of the Household Weight—Despite the weighting efforts and the nonresponse adjustments, the estimated number of households with children is unlikely to perfectly match the population sampled. Any discrepancies are likely to be due to random sampling error and nonrandom response biases. Among these biases may be increased nonresponse based on household size or income, for example. The previous nonresponse adjustments used completed screener interviews to adjust for incomplete screeners, and therefore assume that households with completed screeners are similar to households with incomplete screeners. Poststratification adjusts the weights to match population control totals for key demographic information obtained from an independent source.

For the National Survey of CSHCN, the independent source was the 2000 Census count of households with children. July 2001 is the midpoint of the data collection period for the National Survey of CSHCN data file. The projection of Census data to that date was accomplished by taking 12.5% of the difference between the 1990 Census and the 2000 Census and adding that amount to the 2000 total.

While state-by-state counts of households with children were available from the Census, more detailed data were not available at the time that the weighting was planned. In order to identify demographic subgroups, the Current Population Survey (CPS) was used instead. Proportions were determined using an average of the 1999 CPS March Supplement, the 2000 CPS March Supplement and the 2001 CPS March Supplement; this averaging was intended to produce more stable estimates for the control totals.

By combining the Census population counts with the CPS proportional estimates, the National Survey of CSHCN household, state-level weights were adjusted so that the sum of the weights equals the 2000 Census population counts projected to July, 2001 for the following groups:

- Number of households with one, two, and three or more children
- Number of households with children in each of three non-overlapping race/ethnicity categories
- Number of households with children in each state and the District of Columbia
- Number of households with children that have a household income in each of five non-overlapping categories
- Number of households with children that have non-resident mothers, and number of households with children that have resident mothers in each of four non-overlapping educational attainment categories

The poststratification adjustment also adjusts for the potential bias that may exist because the National Survey of CSHCN, as a telephone survey, could not select households without a telephone at the time of the survey. To make this adjustment, the poststratification control totals from the CPS were split: one control total for telephone households with children and one control total for those without telephones or with an interruption in telephone service for at least one week during the past 12 months. The proportion allocated to each group was based on the average from 1999, 2000 and 2001 CPS data for households with children without telephones and the National Survey of CSHCN data for households with interrupted telephone service. The reason for the use of households with interrupted telephone service in the weighting process is as follows. There is evidence to suggest that households with telephones at the time of the survey, but with interruptions in telephone service during the year, are more similar to households with no telephone service at the time of the survey than households with uninterrupted telephone service during the year (Keeter, 1995; Brick et al., 1996; Frankel et al., 2000). Therefore, nonresponse by nontelephone households can be somewhat compensated for by proportionately increasing the weights for those interviews that could be completed in households with interrupted service. In this way, completed interviews in households with interrupted service represent the incomplete interviews in households without telephone service at the time of the interview.

Truncation of Large Household Weights—Extremely large weights were truncated in order to prevent a small number of cases with large weights from having undue influence on the estimates. The technical appendix describes how the weights were truncated.

Child Screener Weight

A child screener weight was generated for analysis of information available from the screener interview. For example, the proportion of children with a special health care need would be weighted using the child screener weight. Demographic information and information regarding special health care needs status is collected for each resident child. The weight for screened children begins with the final household weight, but is then adjusted so that the final child screener weight sums to the number of children in the nation, as estimated from the Current Population Survey. This poststratification process is described below.

Poststratification of the Child Screener Weight—Despite the weighting efforts and the nonresponse adjustments, the estimated number of children is unlikely to perfectly match the population sampled. Any discrepancies are likely to be due to random sampling error and non-random response biases. Among these biases may be increased nonresponse based on age, sex, or race of the child. Poststratification adjusts the weights to match population control totals for key demographic variables obtained from an independent source.

For the child screener weight, the independent source was the projected 2000 Census count of children. The CPS March Supplement data (averaged across 1999, 2000 and 2001) were used to produce proportions for the demographic items of interest. The child screener, state-level weights were adjusted so that the sum of the weights equals the 2000 Census population counts projected to July, 2001 for the following groups:

- Number of male and female children in three age categories
- Number of children in each of five non-overlapping race/ethnicity categories
- Number of children residing in each state and the District of Columbia
- Number of children in households with one, two, and three or more children
- Number of children in households that have a household income in each of five non-overlapping categories
- Number of children who have non-resident mothers, and number of children who have resident mothers in each of four non-overlapping educational attainment categories

The poststratification control totals from the CPS were split into children in households that have telephones and children in households with an interruption in telephone service for at least one week during the past 12 months. The proportion allocated to each group was based on the 1999 and 2000 CPS data for children in households without telephones and the National Survey of CSHCN data for children in households with interrupted telephone service.

Truncation of Large Screener Weights—Extremely large weights were truncated in order to prevent a small number of cases with large weights from having undue influence on the estimates. The technical appendix describes how the weights were truncated.

Child Interview Weight

A child interview weight was generated for analysis of information available from the interview. For example, the proportion of children with health insurance or the proportion of CSHCN with barriers to needed care would be weighted using the child interview weight. This weight also begins with the poststratified, adjusted household weight. This weight is adjusted for

interview nonresponse and for the number of children in the household. The adjusted weight is poststratified so that the final child interview weight sums to the number of children in the nation, as estimated from the Current Population Survey.

Fourth Form of Nonresponse: Sampled Children for whom an Interview is Not Completed—When a child has been sampled, two results are possible:

- An interview is completed.
- An interview is not completed.

The completed child interviews must represent the children who were sampled, but did not complete the interview. When the number of incomplete interviews is large, the weight for each completed child interview must be increased a great deal. When the number of incomplete interviews is small, the weight for each completed child interview must be increased only slightly. This proportional adjustment is the fourth unit nonresponse adjustment.

The size of the adjustment is based on the size of the two categories, and is calculated simply as the ratio of the total number of sampled children to the number of completed interviews. This adjustment varies based on geographic area. In other words, based on the frequency of nonresponse among sampled children in a given area and in a given sample, compensation is made for this nonresponse by proportionately increasing the weights for those interviews that could be completed in that area. The completed interviews, therefore, represent the sampled children with incomplete interviews.

The logic of this adjustment is the same regardless of whether the child was sampled for a special-needs interview or a health insurance control sample interview. However, the adjustment was calculated separately depending on whether the weight was attached to a completed special-needs interview or a completed health insurance control sample interview. The completed special-needs interviews, therefore, represent the sampled CSHCN with incomplete interviews, and the completed health insurance control sample interviews represent the sampled children without special needs with incomplete interviews.

Adjustment for Multiple-Child Households—One child with special health care needs was randomly selected from among all children with special needs in the household, and one child without special needs was randomly selected from among all children without special needs in the household. In households with multiple eligible children, the randomly selected child represents all of the non-selected children in the household. Therefore, the sampling weight for this completed interview must be increased to reflect the fact that this completed interview "represents" multiple children in that household.

This adjustment simply multiplies the adjusted child weight (which is the household weight adjusted for nonresponse in the interview) by the number of eligible children in the household. For completed interviews with CSHCN, the multiplier is the total number of CSHCN in the household. For completed interviews with children without special needs, the multiplier is the total number of children without special needs in the household.

Poststratification of the Child Interview Weight—The poststratification of the child interview weight is similar to that of the child screener weight because the population of inference is the same: all children in the U.S. The child interview weight is further poststratified so that the proportion of CSHCN in the weighted interview file matches the proportion observed in the

weighted child screener file. This final dimension is determined by using the final, poststratified child screener weight to estimate the national proportion of CSHCN.

Truncation of Large Interview Weights—Extremely large weights were truncated in order to prevent a small number of cases with large weights from having undue influence on the estimates. The technical appendix describes how the weights were truncated.

Quality Control

Staff compared the formulas for the weights and adjustments developed by the sampling statistician with the actual weights and adjustments constructed by the statistical programmer. The variables delivered by the data collection staff to the statistical programmer were used in independent calculations of the weights, in order to check the programmer's implementation of the statistician's weighting specifications.

In addition to this independent check, univariate statistics were produced and reviewed for the adjustments and weights. Reviewers used general knowledge about the size of the population and expectations for IAP-area behavior. For example, interview cooperation rates are typically lower in certain IAP areas (e.g., urban centers) than others (e.g., states in the South and Midwest). This tendency was borne out in the National Survey of CSHCN. In addition, the sums of the various weights were compared to ensure that the differences were in the expected direction (e.g., the sum of the child weights is larger than the sum of the household weights).

Data Files

Four separate but linkable SAS (v8) data files were created based on the completed interviews. The files reflect all data collected during the survey field period with the exception of variables or records suppressed to protect the confidentiality of the respondents. These data sets are:

Screener File—This file contains one record for each child less than 18 years of age residing in a household where the CSHCN Screener was completed. An age-eligible household is defined as one with at least one child who is less than 18 years of age. The screener was determined to be complete if question FACCT5_A (“Has the child’s emotional, developmental or behavioral problem lasted or is it expected to last 12 months or longer?”) had a non-missing value for that child. Incomplete screening interviews are not included in this file. This file (n = 372,174) includes the answers to the CSHCN Screener as well as the child’s age, sex, race, ethnicity, and state of residence. Except for the household identification number, the variables in this file are limited to those assessed at the child level. This file can be used to produce estimates of the proportion of children who have special health care needs and for most demographic characteristics of those children.

Household File—This file contains one record for each age-eligible household screened, regardless of whether a detailed special-needs interview or a brief health insurance control sample interview was completed. This file (n = 196,888) includes all information about the household, including state of residence, household size, total number of CSHCN living in the household, household income (reported relative to the Federal Poverty Level), and whether or

not the household resides in a Metropolitan Statistical Area. All variables in this file are at the household level. This file can be used to produce estimates of the proportion of households that contain at least one CSHCN and for characteristics of those households.

CSHCN Interview File—This file contains one record for each CSHCN who was randomly sampled to be the subject of the detailed special-needs interview and for whom an interview was completed. It should be noted that not all CSHCN selected for an interview at the screener level went on to complete an interview. This file (n = 38,866) includes all information from the detailed interview, including the relationship of the respondent to the sampled child, health and functional status, access to care, experience with care, adequacy of care, health insurance, and the impact of the special health care need on the family. This file can be used to produce a wide range of estimates of the health of CSHCN.

Insurance Analysis File—This file contains one record for each child who was randomly sampled to be the subject of the detailed special-needs interview or the brief health insurance control sample interview and for whom such an interview was completed. Not all children selected for an interview at the screener level went on to complete an interview. This file (n = 215,162) includes a series of health care coverage summary variables for each child. In addition, for eligible children, this file contains all information from the Low-Income Uninsured Supplement, including the brief set of health status and health care utilization variables that were included in this supplement. (For CSHCN, the health care coverage, health status, and health care utilization variables on this file duplicate the information contained on the CSHCN Interview File.) The file can be used to produce estimates of the proportion of children who have various types of health care coverage, to produce a wide range of estimates of the health of low-income uninsured children, and to produce estimates of their parents' knowledge and experiences with Medicaid and S-CHIP.

All four data sets are linkable. Every screened child's household has a corresponding record in the Household File, regardless of whether a detailed interview was completed. Each interviewed child's household has a corresponding record in the Household file, and each interviewed CSHCN has a corresponding record in the Screener File and the Insurance Analysis File. At the household level, the files can be linked using IDNUMR, a unique household identification number. All files contain the IDNUMR variable. At the child level, these files can be linked using IDNUMXR, a unique child identification number. The Screener, CSHCN Interview, and Insurance Analysis Files contain the IDNUMXR variable.

Editing

Concurrent with the development of the CATI questionnaire, a detailed plan for checking and editing the data in the CATI instrument was developed. The intention was to design into the CATI software consistency checks across data elements, valid range codes, and a method to identify incorrect codes entered by interviewers. To the extent that the CATI software could be developed to perform these tasks, the efficiency of post-survey data cleaning and processing was increased.

The CATI system was designed to perform a number of edits as an interviewer enters data into the computer system. These edits dealt with errors that could be reconciled while the

respondent was on the telephone and focused, in particular, on items critical to the conduct of the study. The CATI edit specifications were designed to correct respondent error during the interview (for example, a respondent saying two children lived in the household, but providing only one birth date) and to identify and correct data-entry error by interviewers (for example, a child is reported to have seen a doctor 4 times in the past year, but the interviewer attempts to enter 44 times). To the extent possible without making the CATI system overly complicated, out-of-range and inconsistent responses resulted in a warning screen for the benefit of the interviewer, who was trained to correct errors as they occurred. These messages were designed primarily to prevent data entry errors and respondent errors and not to challenge respondents who gave logically inconsistent responses.

The two main types of CATI edits were range checks and consistency checks. A range violation would result in visual notification to the CATI interviewer (a pop-up box). In most cases the interviewer would have to enter a valid response in order to continue the interview. However, some out-of-range responses would produce a warning, and the interviewer would be instructed to verify the answer provided by the respondent. If the respondent confirmed the out-of-range value, the interviewer was allowed to continue. A consistency violation would also result in a pop-up box indicating that an inconsistency between two responses had been detected. The interviewer would then have the opportunity to change one or both of the values entered. In some cases the interviewer had the option to proceed if the respondent confirmed the inconsistent values. There are trade-offs between, on the one hand, incorporating every possible type of error check into a CATI system and, on the other hand, overall performance of the CATI system and the use of development resources. To reconcile this trade-off, post-CATI edits were developed to resolve problems that did not require access to the respondent. Any problems that could not be resolved without further access to the respondent were left inconsistent.

After the pre-programmed edits were run, the first step in the data cleaning process was verification of the valid number of cases in the data file. After verifying the number of cases, initial data frequencies were produced and reviewed. Each variable's range of permissible values was examined for any additional invalid values or unusual distributions. Invalid values, where they occurred, were blanked out. Nested variables (i.e., variables that are only asked based on a response to a previous question) were linked to their root variables, and questionnaire paths were traced. If blank values already existed for a variable, they were checked to see whether they were allowable (e.g., due to legitimate skip patterns in the questionnaire) or missing in error. Records that were missing responses for unknown reasons were left missing.

Missing Data

The CATI system is designed to minimize missing data. In some instances, however, data are missing. Most analysts ignore records with missing data, regardless of the reasons for the missing data. However, for analysts who may wish to differentiate between different types of missing values, SAS provides a mechanism to do so. The following key provides a description of the various codes that were used to represent missing data in each of the Screener, Household, CSHCN Interview, and Insurance Analysis Files.

(.N) Not in universe (sample logic)—Respondents skipped entire section of questions based on eligibility criteria (e.g., special health care needs, demographic characteristics).

(.L) Legitimate skip (question logic)—Respondents skipped one or more questions within a section because of an answer selected for a root question.

(.P) Partially completed case—Question not answered because the respondent broke off the interview prior to completing this question. A partial complete indicates the interview was completed at least through the end of Section 7. These cases are included in the CSHCN Interview and Insurance Analysis Files, even though data are missing for questions that were asked late in the interview.

(.M) Missing in error—A response should have been captured for this question, but was not. Data may be missing in error if records were not properly transferred or stored after a case was finished, the rules for returning to a previous question were not properly followed by an interviewer, or the recorded answer was determined to be invalid.

(.A) Added question—This question was added after the start of data collection and the respondent was interviewed before the question was added to the interview. Questions added after the start of data collection include items regarding mother’s education, mother’s residence, transitional health care and vocational needs for CSHCN reaching adulthood, reasons for not enrolling the sampled child in Medicaid or S-CHIP programs, and a follow-up question concerning whether reported insurance was provided through an employer.

(.B) Break off after a screener was completed—If a screener was completed for the household, but a detailed special-needs interview or a health insurance control sample interview was not completed, the record will be missing some household demographic data that are gathered only at the end of the interview. This value is used only in the Household File to indicate why no data exist for such cases.

(.X) No recoded response—These cases did not have a recoded verbatim response for this variable. (For a further explanation, see “Coding of Verbatim Answers” below.)

Because SAS treats all of the above codes similarly in statistical analyses (i.e., as missing data), analysts using SAS who are not interested in the reasons for the missing data may continue to analyze data as usual.

It is important to note that derived variables (i.e., variables whose response was not directly provided by the respondent) do not include the detailed coding of missing data. All missing values for derived variables received a “.M,” regardless of the reason for the missing data. Similarly, “.M” was used when derived variables were suppressed to protect the confidentiality of the survey participants.

Data missing because the respondent did not know the answer or refused to provide the answer have been treated differently. Rather than assigning a missing value to these records, a numeric code was used to identify these responses. Typically, unknown answers are coded as “6,” “96,” or “996.” Refused responses are coded as “7,” “97,” or “997.” However, the codes may be different for specific variables; therefore, analysts are encouraged to consult the data documentation and frequency lists to identify the correct codes for each variable. Failure to do so may result in inappropriate calculations, especially for variables measured using ordinal, interval, or ratio scales.

Imputation of Household Income for Uninsured Children

The Low-Income Uninsured Supplement was asked in all households below 200% of DHHS Federal Poverty Guidelines where the sampled child was uninsured. If a respondent refused to provide income or gave a “don’t know” response to the income questions, the CATI system assumed that the respondent’s household was below 200% of the federal poverty level and administered this Supplement if the sampled child was uninsured. Some households with higher incomes will be included in this group. Some analysts interested in uninsured children from only low-income households may wish to exclude households with missing income data before analyzing the Low-Income Uninsured Supplement. Other analysts interested in uninsured children from only low-income households may wish to impute an income value to these cases.

Analysts who desire an imputed income variable for uninsured children with missing income data may use “POV200_I,” which is an indicator that the child’s household is predicted to be below 200% of the federal poverty level. This prediction is based on a logistic regression model built using survey data from uninsured children with reported income data. Details about the calculation and fit of the model are available from NCHS.

When necessary for the calculation of sampling weights, other missing values were imputed. Because the imputed values were developed for weighting purposes rather than analytic purposes, these imputed data have not been included on the data files.

Coding of Verbatim Answers into Question Responses

Beginning in January 2001, 33 open-ended verbatim text boxes were added to the survey, in order to capture more specific information when “other” responses were selected as an answer to a stem question. These text boxes allowed interviewers to record an exact response from the respondent, rather than simply selecting an “other” response with no additional information.

At the end of the data collection period, in collaboration with NCHS and the Urban Institute, every attempt was made to recode the verbatim responses captured into an existing response category in the stem question. A number of new response categories and variables were also added to the interview data file, to reflect common responses that were not part of the original set of response categories. For reference, these added response categories and variables have been included in the final CATI specifications (Appendix II) after the “other” category in lists of response options; these categories were not available to interviewers during questionnaire administration. When recoding was not necessary for a particular record, or when the new variable was not relevant to the verbatim response given, “.X” was assigned as the missing value.

Edits to Protect Confidentiality

NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. The risk of inadvertent disclosure of confidential information about individual respondents is higher with a publicly released data set having detailed geography variables, a detailed and extensive set of survey observations, and a sizeable proportion of the total population of interest. Coarsening a data set by suppressing survey variables, collapsing multiple variables into one, collapsing response categories for other variables, and/or

introduction of noise in the data are common techniques to reduce the risk of inadvertent disclosure.

In these data files, household income has been suppressed, but a measure of income relative to the federal poverty level has been included. Hispanic origin (yes/no) has been reported separately from race, but specific Hispanic origin (e.g., Mexican) has been suppressed. The specific language of the interview has been suppressed, but an indicator has been included to identify interviews that were not conducted entirely in English. The relationship of the respondent to the child has been suppressed when the respondent was not the parent of the child.

Geography—Geographic information that would identify the specific IAP area in states with multiple IAP areas has been suppressed. However, state identifiers are included in all files. In addition, an indicator identifying whether or not the household resides inside or outside of a Metropolitan Statistical Area (MSA) has been included for some states. This indicator was suppressed whenever the population for either the MSA areas or the non-MSA areas was less than 500,000 persons. This resulted in the suppression of the MSA identifier in 16 states. The MSA identifier was suppressed in Connecticut, Delaware, Hawaii, Massachusetts, Maryland, New Hampshire, Nevada, and Rhode Island because the non-MSA population was too small. The MSA identifier was suppressed in Idaho, Maine, and Montana because the MSA population was too small. The MSA identifier was suppressed in Alaska, North Dakota, South Dakota, Vermont, and Wyoming because both the non-MSA population and the MSA population were too small.

Race—Respondents were permitted to identify all possible categories that described the child's race. Nationally, responses for the race variable have been collapsed to four categories: white only, African-American or black only, other race, and multiple race. The "other race" category includes children for whom only one of the other three categories (Asian, Native American/Alaska Native, and Native Hawaiian/Other Pacific Islander) was reported. Children for whom more than one race was identified (e.g., Asian and Native Hawaiian) were included in the "multiple race" category. The "other race" category also includes children for whom a single verbatim response was provided that could not reliably be coded to a particular race. Examples of these responses are Central American, Brazilian, and Puerto Rican. The coding of verbatim responses to racial categories was based on Census guidelines.

In several states, however, minority group populations are sufficiently large that the release of additional race categories was possible. To identify these states, data from the decennial 2000 census were examined to identify minority groups that comprise at least five percent of the total population of children in the state. Based on this criterion, the data files identify Native American and Alaskan Native children in Alaska, Arizona, Montana, New Mexico, North Dakota, Oklahoma, and South Dakota. Asian children's race is reported for children in California, New Jersey, New York, and Washington. The data files identify both Asian children and Native Hawaiian and Pacific Islander children in Hawaii.

Number of children in household—The CSHCN Screener data and demographic information were collected for every child in every household with children. However, the information on the total number of children in each household significantly increases the risk of inadvertent disclosure of confidential information in households with large numbers of children. Therefore, the number of children reported to be living in a household was top-coded to suppress the

identity of large households, with the specific top code determined by state. To determine the top code for a particular state, weighted data from the decennial 1990 Census were used to estimate the proportion of households with children in each state that include six or more children. If at least $\frac{1}{2}$ of 1 percent of the population of households with children included six or more children, then a top code of six children was used for that state. Otherwise, a top code of five children was used. (In all states, at least $\frac{1}{2}$ of 1 percent of the population of households with children included five or more children.) This resulted in 21 states with a top code of five children. To complete the masking of households with a large number of children, records in the Screener File were suppressed at random from these large households to achieve the 5- or 6-child state-dependent threshold in each of these large households. Only children who were not the subject of a detailed special-needs interview or a health insurance control sample interview were eligible for suppression.

From the 373,055 records in the original Screener File, 881 records (0.2%) were suppressed. Sampling weights for the remaining records in the Screener File were adjusted to ensure that estimates for the prevalence of CSHCN in each state, and for the prevalence of CSHCN from large households in each state, were unchanged. Weights for the suppressed records in each state were summed based on the child's special-needs classification (i.e., with or without special needs) and then redistributed by special-needs status to the screening records that remained for the households with large numbers of children in that state. That is, weights for suppressed CSHCN from large households were reallocated to remaining CSHCN from large households, and weights for suppressed non-CSHCN from large households were reallocated to remaining non-CSHCN from large households. This reallocation of weights was accomplished using a ratio adjustment for the weights of the remaining records, with the exception that weights for children who were the subjects of a detailed special-needs interview or a health insurance control sample interview were left unchanged.

Age—In these data files, both the child's date of birth and the date of the interview have been suppressed, but the child's age (in years) at the time of the interview has been reported. A risk of inadvertent disclosure exists in households with multiple children of the same age (e.g., triplets, quadruplets) and in households with multiple sets of children of the same age (e.g., two sets of twins). Randomly adding a year of age to or subtracting a year of age from randomly selected children in selected households masked these records. Of the 196,888 households screened, the ages of children in 131 households were adjusted.

Other—Several other frequency variables have been top-coded to suppress outliers at the high end of the distribution of responses. Due to their unusual characteristics, records including these outliers might have been more readily identifiable.

- For number of doctor visits for any reason in the past year for CSHCN (C6Q01R), 21 visits or more is the maximum reported and responses between 11 visits and 20 visits have been collapsed into two categories (11-15, 16-20).
- For number of doctor visits for any reason in the past year for non-CSHCN eligible for the Low-Income Uninsured Supplement, 11 visits or more is the maximum reported.
- For number of days missed from school due to illness or injury (C3Q14R), 11 days or more is the maximum reported.

- For hours per week providing health care at home for the child (C9Q03R), 21 hours or more is the maximum reported and responses between 11 hours and 20 hours have been collapsed into a single category.
- For hours per week arranging or coordinating care for the child (C9Q04R), 21 hours or more is the maximum reported and responses between 11 hours and 20 hours have been collapsed into a single category.
- For the total number of adults living in the households (TOTADULT), 4 adults or more is the maximum reported.
- For the education level of the child's mother (MOTHER_EDUCR), bachelor's degree or more advanced study is the maximum reported and other responses have been collapsed into four additional categories (no more than 8th grade education, some high school completed but no high school diploma or GED, high school graduate or GED completed, associate's degree or some college completed).

Analysts interested in working with data that were suppressed to protect confidentiality may access unmodified data files through the NCHS Research Data Center (RDC). This facility, designed for the researcher outside of NCHS, is located in Hyattsville, Maryland. Data files housed in the RDC may also be accessed remotely via e-mail. For more information about how to apply for access, analysts may visit their website at <http://www.cdc.gov/nchs/r&d/rdc.htm>.

Derived Variables on the Screener File

AGE—The child's age in years was derived from the reported month, day, and year of each child's birth in question C2Q01. In cases where a valid value for the year of birth was not provided, the respondent was asked for the child's age in months (C2Q02) and/or years (C2Q02A). To calculate the age for each child, the date of birth was compared to the date that the child was first identified as eligible (which may have been prior to the date that the actual interview was completed). Valid values for AGE are 0 through 17, where "0" means younger than one year. For some cases, a valid age in years could not be calculated; the respondent did not know or refused the child's date of birth or age. These cases are coded as missing (.M).

HISPANIC—This indicator of whether the sampled child is of Hispanic or Latino origin was derived using data collected in variables C1001_01 through C1001_10 and CW10Q01A. Respondents who did not identify a Hispanic ethnicity during administration of C1001_01 through C1001_10, but did provide an answer indicating Hispanic ethnicity as part of a verbatim response to the race question were coded with a value of "1" for the variable HISPANIC.

INTVIEW—This is an indicator that either a detailed special-needs interview or a health insurance control sample interview was completed for the screened child.

NEEDTYPE—The special-needs status of each child was derived from responses to the CSHCN Screener (FACCT1, FACCT1_A, FACCT1_B, FACCT2, FACCT2_A, FACCT2_B, FACCT3, FACCT3_A, FACCT3_B, FACCT4, FACCT4_A, FACCT4_B, FACCT5, and FACCT5_A).

RACER, RACENAA, RACEASIA, and RACE_HI—These race classification variables were derived using data collected in variables C1002_01 through C1001_08 and CQ10Q02A. Based

on guidelines from the Office of Management and Budget, data from CW10Q03 have been suppressed.

SEX—This indicator was created from C2Q03.

Derived Variables on the Household File

HHSTATUS—This variable indicates whether a detailed interview was completed for any children living in the household.

MSASTATR—This indicator identifying whether or not the household resides inside or outside of a Metropolitan Statistical Area (MSA) was suppressed to protect confidentiality in 16 states.

NM_NSPR—This variable represents the total number of children in the household without a special health care need. As noted previously, some screener records have been suppressed to protect the confidentiality of large households. This variable is based on the screener records that remain, and therefore may be inaccurate for large households.

NM_NSPRF—This variable represents the total number of female children in the household without a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_NSPMR—This variable represents the total number of male children in the household without a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_SPR—This variable represents the total number of children in the household with a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_SPRF—This variable represents the total number of female children in the household with a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

NM_SPMR—This variable represents the total number of male children in the household with a special health care need. As noted for NM_NSPR, this variable also may be inaccurate for large households.

OTH_LANG—This flag that can be used as a proxy indicator that the interview was administered in a language other than English. For sample management purposes, a calling queue was used for households identified as requiring an interviewer capable of conducting a non-English screener/interview. This flag, OTH_LANG, indicates such households. If, on subsequent calls, the screener or interview was conducted in English, this flag was not reset. However, past research demonstrated that the flag reliably indicated the language of interview administration in over 97% of cases.

POVLEVEL—This indicator was created using total household members (C11Q01_A) and the household income value. If data for either of these two components were missing, refused, or had a “don’t know” response, this measure was assigned a missing value code. The household income value was the actual dollar amount reported by respondents who reported an exact household income (C11Q01). However, when respondents did not supply a specific dollar amount for household income, it was necessary to go through a series (i.e., cascade) of questions asking respondents whether the household income was below, exactly at, or above threshold amounts (W9Q02 through W9Q12A). If respondents did not complete the income cascade, either because they refused or did not know the answer to one of the cascade questions, this measure was assigned a missing value code. Once an income-to-household-size measure was computed, it was compared with DHHS Federal Poverty Guidelines. More detail about the development of this poverty indicator is available in Appendix IV.

TOTADULT—The total number of adults in the household was derived by subtracting the total number of children in the household from the total number of persons in the household (C11Q01_A). During data collection, the CATI system did not reconcile the total number of persons reported as living in the household with the total number of children reported in that household. Therefore, the number of children screened in a single household could be greater than the total number of persons reported as living in the household. When this occurred, the total number of adults was assigned a missing value code (.M).

TOTKIDSR—This variable represents the total number of children aged 0 to 17 in the household. As noted for NM_NSPR, this variable also may be inaccurate for large households.

TOTKIDFR—This variable represents the total number of female children aged 0 to 17 in the household. As noted for NM_NSPR, this variable also may be inaccurate for large households.

TOTKIDMR—This variable represents the total number of male children aged 0 to 17 in the household. As noted for NM_NSPR, this variable also may be inaccurate for large households.

Derived Variables on the CSHCN Interview File

C6Q01R—The number of visits to a doctor or other health care provider was derived from C6Q01.

HPCARE1F and HPCARE2F—These flags indicate whether the interviewer accessed a question-specific, online job aid with supplemental information regarding professional care coordination.

Derived Variables on the CSHCN Interview and the Insurance Analysis Files

Because the child’s type of health insurance coverage could be reported several ways within the health insurance section of the questionnaire, categorical indicators have been derived to simplify analyses of coverage type. Because lack of health care coverage could be reported several ways, categorical indicators have also been derived to simplify analyses of uninsurance at

the time of the survey, uninsurance during the year prior to the survey, and the length of the uninsurance spell (for currently uninsured children).

CHIPNAME—This flag indicates whether an SCHIP program name could be provided to respondents for the state in which the sampled child resides. An SCHIP program name could not be provided if the state does not offer SCHIP insurance or if the state’s SCHIP program shares the same name as the Medicaid program. CHIPNAME also indicates if the name of the state’s Medicaid expansion program was provided instead of the SCHIP program name.

MEDICAID—Medicaid coverage was reported, either directly (C7Q01 or C7Q10_01) or by State Medicaid program name (C7Q08 or C7Q10C). In eight states, Medicaid coverage may also have been reported at C7Q02. For more details, see the description of the SCHIP variable.

MILITARY—Some type of military coverage was reported, either directly (C7Q04 or C7Q10_06), by military program name (C7Q08 or C7Q10C), or by naming a program that is supplemental to TRICARE or CHAMPUS (C7Q08 or C7Q10C).

NATIVINS—Comprehensive services from a facility supported by the Indian Health Service or a Native American Corporation were reported, either directly (C7Q10_07) or by program name (C7Q08 or C7Q10C).

OTHERINS—Comprehensive insurance coverage other than Medicaid, S-CHIP, Title V, private, or military coverage was reported. This category includes Medicare (C7Q10_02 or C7Q10_05). The category also includes cases where a respondent reported (in C7Q08 or C7Q10C) an apparently valid plan name (e.g., Aetna, Blue Cross Blue Shield) or a valid plan type (e.g., HMO, IPA), but where this insurance could be obtained by either private or public means. To be included in this category, the reported insurance was required to cover both doctor visits and hospital stays (C7Q08A or C7Q10B).

OTHPUB—The coverage reported (in C7Q08 or C7Q10C) could not be classified reliably as Medicaid or S-CHIP, but it was clear from the response that it was publicly obtained.

PRIVATE—Comprehensive private coverage was reported, either directly (C7Q03 or C7Q10_08) or by naming a program or program type (e.g., PPOs) that can only be privately obtained (C7Q08 or C7Q10C). This category also includes insurance provided by an employer or union, as indicated by the verbatim response to C7Q08 (e.g., “Teamster’s insurance”) or by C7Q08B. To be included in this category, the reported insurance was required to cover both doctor visits and hospital stays (C7Q03A or C7Q08A or C7Q10A or C7Q10B).

SCHIP—SCHIP coverage was reported, either directly (C7Q02 or C7Q10_04) or by State SCHIP program name (C7Q08 or C7Q10C). In eight states, C7Q02 asked about the state’s Medicaid expansion program. These states are Alaska, Arkansas, District of Columbia, Idaho, Louisiana, Nebraska, New Mexico, and Wisconsin (see CHIPNAME). In these states, affirmative responses to this variable include insurance obtained through the Medicaid expansion program. If states did not offer SCHIP insurance or if the state’s SCHIP program shares the same name as the Medicaid program, the SCHIP indicator was set to a missing value.

SINGLINS—The insurance reported, either directly (C7Q10_09) or indirectly (C7Q08 or C7Q10C), could be classified as covering only a single type or single place of service. Examples of insurance covering single types of service include dental, vision, and accident coverage. An example of insurance that covers a single place of service is foreign government insurance (e.g., the Mexican Social Security System). This category also includes special discount programs offered by some service providers (e.g., Healthy Options Card), and special funding sources (or "pools" of money) that permit certain providers to recoup some of their medical costs (e.g., Amish Aid Society, Colorado Indigent Care Program).

TITLEV—Title V coverage was reported, either directly (C7Q06 or C7Q10_03) or by Title V program name (C7Q08 or C7Q10C).

UNKINS—The respondent reported coverage in C7Q08 or C7Q10C that could not clearly be classified as comprehensive. Examples include school, family, and supplemental coverage. This category also includes cases where the respondent reported an unknown acronym (e.g., PPL, PTO).

UNINS—This variable indicates that the child was uninsured at the time of the survey. A positive value for this variable indicates that the respondent did not report any insurance coverage; reported coverage, but indicated that it was not comprehensive; or reported only native insurance or single type/place insurance.

UNINS_YR—This variable indicates that the child was uninsured at the time of the survey or at some time during the 12 months prior to the survey.

MS_UNINS—This variable, which indicates the number of months without coverage during the 12 months prior to the survey, was derived from C7Q11, C7Q12, C7Q13, and C7Q14. This variable was not ascertained if the respondent reported an insurance type that was not considered comprehensive insurance (e.g., by reporting Indian Health Service coverage at C7Q10_07, by reporting a single service plan at C7Q10_09, by reporting non-comprehensive private insurance at C7Q10A, by reporting a plan type at C7Q08 or C7Q10C that could not be classified as comprehensive). If a child was less than 12 months of age and was uninsured for his/her entire lifetime, MS_UNINS was set to 12 months.

YS_UNINS—This variable, which indicated the number of years since an uninsured child was last insured, was derived from C7Q13. This variable was not ascertained if MS_UNINS was not ascertained, and this variable is missing for children who are currently insured and for children who have been uninsured for less than 12 months. There is one exception. If a child was less than 12 months of age and was uninsured for his/her entire lifetime, YS_UNINS was set to "never insured."

MOTHER_EDUCR—The highest level of education attained by the mother of the sampled child was derived from C2Q04, CW10Q04, and CW10Q04A.

RELATION—Information collected in question C2Q04 regarding the relationship of the respondent to the sampled child has been collapsed into three categories.

Dummy Variables

When respondents were permitted to provide multiple answers for the same question, a variable was created for each possible answer. The values for these new dummy variables are “yes, this answer was given,” and “no, this answer was not given.” When respondents could not or did not provide an answer to the question, a value of “don’t know” or “refused” is reported for each of the dummy variables.

- C4Q5_1B is represented by C4Q5_1B1 to C4Q5_1B16.
- C4Q5_2B is represented by C4Q5_2B1 to C4Q5_2B16.
- C4Q5_3B is represented by C4Q5_3B1 to C4Q5_3B16.
- C4Q5_4B is represented by C4Q5_4B1 to C4Q5_4B16.
- C4Q5_5B is represented by C4Q5_5B1 to C4Q5_5B16.
- C4Q5_6B is represented by C4Q5_6B1 to C4Q5_6B16.
- C4Q5_7B is represented by C4Q5_7B1R to C4Q5_7B6R and C4Q5_7B7 to C4Q5_7B16.
- C4Q6_1B is represented by C4Q6_1B1 to C4Q6_1B16.
- C4Q6_2B is represented by C4Q6_2B1 to C4Q6_2B16.
- C4Q6_3B is represented by C4Q6_3B1 to C4Q6_3B16.
- C7Q15 is represented by C7Q15R01 to C7Q15R10.
- C12Q1A is represented by C12Q1A01 to C12Q1A25.
- C12Q6B is represented by C12Q6B01 to C12Q6B12.
- C13Q61B is represented by C13Q61B1R to C13Q61B16R.
- C13Q62B is represented by C13Q62B1R to C13Q62B16R.
- C13Q63B is represented by C13Q63B1R to C13Q63B16R.
- C13Q64B is represented by C13Q64B1R to C13Q64B16R.
- C13Q65B is represented by C13Q65B1R to C13Q65B12R.
- C13Q66B is represented by C13Q66B1R to C13Q66B16R.
- C13Q67B is represented by C13Q67B1R to C13Q67B16R.

Additional Data Notes

If a respondent refused to provide income or gave a “don’t know” response to the income questions, the CATI system assumed that the respondent’s household was below 200% of poverty and was to administer the question about cash assistance (C11Q11) for these households. A programming error in the system resulted in missing data on this question for 183 cases with missing income.

The question about the mother’s residence (C2Q04_A) was not added to the CATI instrument until late in 2000. For interviews completed before the question was added, this variable was coded to indicate that the mother lived with the child if the respondent was identified as the sampled child’s mother. Otherwise, the special code for added questions (.A) was used to define cases where data are missing because the interview was completed before the question was added.

Several questions in the special-needs interview were applicable only for children of certain ages. The CATI system was programmed to ask only the age-appropriate questions. However, for unknown reasons, a small number of children received questions that were not appropriate for their ages. Adjustments during data cleaning corrected for these errors:

- C3Q12R was created from C3Q12;
- C3Q13R from C3Q13;
- C4Q05_07R from C4Q05_07;
- C4Q5_7AR from C4Q5_7A;
- C4Q5_7B1R from C4Q5_7B1;
- C4Q5_7B2R from C4Q5_7B2;
- C4Q5_7B3R from C4Q5_7B3;
- C4Q5_7B4R from C4Q5_7B4;
- C4Q5_7B5R from C4Q5_7B5;
- C4Q5_7B6R from C4Q5_7B6;
- C4Q05_11R from C4Q05_11;
- C4Q5_11AR from C4Q5_11A;
- C4Q05_12R from C4Q05_12;
- C4Q05_12AR from C4Q05_12A;
- C6Q0AR from C6Q0A;
- C6Q0A_AR from C6Q0A_A;
- C6Q0A_BR from C6Q0A_B; and
- C6Q0BR from C6Q0B.

In addition, a programming error resulted in the omission of the question on early intervention services (C3Q12) for CSHCN who were two years of age (24-35 months) at the time of the interview.

Estimation And Hypothesis Testing

The National Survey of CSHCN data were obtained through a complex sample design involving clustering of children within households and stratification of households within states. To produce estimates that are representative of children nationally and within each state, sampling weights must be used. These sampling weights were developed to account for complex sample design and include adjustments for multiple-telephone households, unit nonresponse, and noncoverage of nontelephone households, as well as adjustments to known population control estimates.

As described earlier, three sampling weights have been developed for the National Survey of CSHCN. These weights should be used for both national and state-level analyses.

Household weight (WEIGHT_H)—This weight is on the Household File and is used for producing estimates that are representative of households with children nationally and within each state. A household weight has been associated with every age-eligible household screened. This weight should be used only when the unit of analysis is the household.

Screener weight (WEIGHT_S)—This weight is on the Screener File and is used for producing estimates that are representative of children nationally and within each state. A screener weight

has been associated with every child screened, regardless of whether a detailed special-needs interview or a brief health insurance control sample interview has been completed. This weight should be used only when the unit of analysis is the child, and the data analyzed come solely from the Screener File and the Household File.

Interview weight (WEIGHT_I)—This weight is on the CSHCN Interview File and the Insurance Analysis File. When used with the CSHCN Interview File, this weight produces estimates that are representative of CSHCN nationally and within each state. When used with the Insurance Analysis File, this weight produces estimates that are representative of children nationally and within each state. An interview weight has been associated with every child interviewed. This weight should be used only when the unit of analysis is the child and the data analyzed include variables that are on the CSHCN Interview File or the Insurance Analysis File.

Variables Used for Variance Estimation

Because of the complex design of the National Survey of CSHCN, the household records and the child-level screener and interview records have unequal weights. Therefore, statistical software programs that assume simple random sampling will most often compute standard errors that are too low. Tests of statistical hypotheses may then suggest statistically significant differences or associations that are misleading. However, computer programs are available that provide the capability of variance estimation for complex sample designs (e.g., SUDAAN, Stata, WesVar). In order to provide the user with the capability of estimating the complex sample variances for the National Survey of CSHCN data, we have provided stratum identifiers and primary sampling unit (PSU) codes on the data files. These variables and the sample weights are necessary for the calculation of variances.

It should be noted that the stratum identifiers reported on the data set are not identical to the strata used for drawing the sample. In states with multiple Immunization Action Plan (IAP) areas, independent samples were selected from each IAP area in proportion to the total number of households with children in each IAP area. Therefore, these IAP areas should be considered strata for variance estimation. However, disclosure of the specific IAP area for each child (even if the code were scrambled) could increase the risk of disclosure of a respondent's identity. For example, the IAP area with the lowest frequency of responses in New Jersey would be readily identifiable as Newark. In the absence of IAP-specific identifiers, data users should use the state identifier (STATE) as the stratum identifier. By using the state identifier rather than the suppressed IAP identifier, the standard errors for national and state estimates with key variables are affected only slightly, and not in a consistent direction. The PSU for the National Survey of CSHCN is the household and is represented on the data sets by the unique household identifier, IDNUMR.

The overall number of persons in this survey is sufficient for most statistical inference purposes. However, analyses of some rare responses and analyses of subclasses can lead to estimators that are unreliable. Small sample sizes used in the variance calculations may also produce unstable estimates of the variances. Consequently, these analyses require that the user pay particular attention to the coefficient of variation for the estimates of means, proportions, and totals.

Variance Estimation Using SUDAAN

Standard errors for the National Survey of CSHCN can be obtained using the Taylor-series-approximation method, available in software such as SUDAAN, SAS, and Stata. As noted previously, the state should be identified as the stratum variable and the household should be identified as the primary sampling unit.

The simplifying assumption that PSUs have been sampled with replacement allows most complex survey sample design computer programs to calculate Taylor-series standard errors in a straightforward way. This method requires no recoding of design variables, but is statistically less efficient (and therefore more conservative) than some other methods because the PSU unit is treated as being sampled with replacement within the stratum unit. For SUDAAN, the data file needs to be sorted by stratum (STATE) and PSU (IDNUMR) prior to invoking SUDAAN. The following SUDAAN design statements are used for analyses at the household level:

```
PROC . . . DESIGN = WR;  
  NEST STATE IDNUMR;  
  WEIGHT WEIGHT_H;
```

For analyses of the Screener File data at the child level, replace “WEIGHT_H” with “WEIGHT_S”. For analyses of the CSHCN Interview File or Insurance Analysis File data, replace “WEIGHT_H” with “WEIGHT_I”.

It should be noted that other variance estimation procedures are also applicable to the National Survey of CSHCN. Specifically, the jackknife method with replicate weights and the bootstrap resampling method with replicate weights can also be used (via software such as WesVar) to obtain standard errors that fully reflect the impact of the weighting adjustments on standard errors.

Variance Estimation for Subsets of the Data

Most analyses of the National Survey of CSHCN data will focus on specific population subgroups, such as CSHCN in only one state or CSHCN living in poverty. Some analysts will therefore be tempted to delete all records outside of the domain of interest in order to work with smaller data files and run computer jobs more quickly. This procedure of keeping only select records and list-wise deleting other records is called subsetting the data. Subsetted data that are appropriately weighted can be used to generate correct point estimates (e.g., estimates of population subgroup frequencies or means), but most software packages that analyze complex survey data will incorrectly compute standard errors for subsetted data. When complex survey data are subsetted, the sample design structure is often compromised because the complete design information is not available. Subsetting the data can delete important design information needed for variance estimation (e.g., deleting all records for certain subgroups may result in entire PSUs being removed from the design structure).

The National Survey of Children with Special Health Care Needs was designed to provide independent data sets for each the 50 states and the District of Columbia. Subsetting the survey data to a particular state does not compromise the design structure of the survey. That is, standard errors calculated in SUDAAN for a particular state will not be affected if the data set has been subsetted to that particular state.

However, subsetting to specific population subgroups (within or across states) can result in incorrect standard errors. For example, subsetting the data to those CSHCN who live in poverty within a specific state will result in incorrectly calculated standard errors. Typically, the standard errors for subsetting data will be inflated, resulting in a higher probability of type-II error (i.e., failing to detect significant differences that do in fact exist). SUDAAN has a SUBPOPN option that allows for the targeting of specific subpopulations for analysis while retaining the full unsubsetting data set that includes the full sample design information. Analysts interested in specific population subgroups are encouraged to use SUBPOPN rather than subsetting the data sets.

Weighted Frequencies, Prevalence Estimates, and Standard Errors

Weighted frequencies of the number of households having a child with special health care needs and the number of CSHCN by state appear in Appendix IX. Prevalence estimates and standard errors are also provided. Analysts may wish to replicate this table to determine if they are using the weights correctly.

Guidelines for Data Use

With the goal of mutual benefit, NCHS requests that recipients of data files cooperate in certain actions related to their use.

Any published material derived from the data should acknowledge NCHS as the original source. The suggested citation, "Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001," should appear at the bottom of all tables. It should also include a disclaimer that credits any analyses, interpretations, or conclusions reached to the author (recipient of the file) and not to NCHS, which is responsible only for the initial data. Consumers who wish to publish a technical description of the data should make a reasonable effort to ensure that the description is not inconsistent with that published by NCHS.

The Public Health Service Act (Section 308d) provides that data collected by NCHS may be used only for the purpose of health statistical reporting and analysis. Any effort to determine the identity of any reported case is prohibited by this law. NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. All direct identifiers, as well as any characteristics that might lead to identification, are omitted from the data set. Any intentional identification or disclosure of a person or establishment violates the assurances of confidentiality given to the providers of the information. Therefore, users must:

- Use the data in this data set for statistical reporting and analysis only.
- Make no use of the identity of any person discovered, inadvertently or otherwise, and advise the Director, NCHS, of any such discovery.
- Not link this data set with individually identifiable data from any other NCHS or non-NCHS data sets.

Use of the data set signifies users' agreement to comply with the above-stated statutory-based requirements.

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Appendix I

Sampling and Sampling Weights Technical Summary

Sample Design

The basic design objective of the National Survey of CSHCN was to select a sample of 750 children with special health care needs less than 18 years of age in each state in the United States plus the District of Columbia. This sample was selected over a period of eighteen months, by first identifying households with children under the age of 18 and then screening within these households for the presence of CSHCN. In all households where CSHCN were present, one such child was selected. In all households where children without special health care needs were present, one such child was also selected. Therefore, the number of children without special health care needs that was selected in a state depended upon the number of households with children that needed to be screened to reach a sample of 750 CSHCN. In households in which both types of children were present, two children (one of each type) were selected. If the sampled children, with or without special health care needs, were uninsured and the household income was below 200% of poverty as determined by the DHHS Federal Poverty Guidelines, the sampled children were also eligible to receive the Low-Income Uninsured Supplement.

Drawing the NIS Sample

The sample of households selected for screening for the National Survey of CSHCN was a subsample of the households screened for the National Immunization Survey (NIS), a continuous list-assisted random-digit-dial (RDD) survey administered in each of 50 state and 28 metropolitan Immunization Action Plan (IAP) areas. Therefore, the sampling design for the selection of households in the National Survey of CSHCN was essentially the same as the design for the selection of households in the NIS. A brief description of the procedure for the selection of households in the NIS is given below. For more detail on the NIS sample design, readers are encouraged to obtain chapter 3 of the 1999 *National Immunization Survey Sample Design Report*, which is available from NCHS. Further information regarding the NIS itself can be found in Zell et al.'s *National Immunization Survey: The Methodology of a Vaccination Surveillance System* (2000).

Associating Telephone Numbers with IAP Areas—To draw a sample of telephone numbers in an IAP area, one must, in effect, compile a list of all telephone numbers that belong to that area. For some IAP areas this step is straightforward. For example, when the IAP area is a state with a single area code, the list would consist of all telephone numbers within the central-office codes that are in service in that area code. (Combined, an area code and a central-office code form a “prefix area.” For example, when a telephone number is 617-555-1234, 617-555 is the prefix area corresponding to the 555 central office in the 617 area code.)

For other IAP areas, however, this step encounters a number of complications. When the IAP area is a city, a county, or a combination of counties, some prefix areas may cover part of the IAP area and part of an adjacent IAP area. In such situations, the NIS applies a plurality rule:

if at least 50% of the directory-listed households in a prefix area fall inside an IAP area, the prefix area is assigned to that IAP area.

Drawing the Initial NIS Sample—The sample frame for an IAP area consists of banks of 100 consecutive telephone numbers within the prefix areas assigned to the IAP area. For example, the numbers from 617-555-7100 to 617-555-7199 constitute a working bank in the 617-555 prefix area. Banks that contain zero directory-listed residential telephone numbers are excluded from the frame because they have very little chance of containing working residential numbers. For this preliminary step, the GENESYS Sampling System (a proprietary product of Marketing Systems Group) uses a file of directory-listed residential numbers from Donnelley Marketing Information Services (DMIS). The result is a file that lists the remaining banks (the “1+ working banks”). From the 1+ working banks, a random sample of complete ten-digit telephone numbers is drawn for each quarter in such a way that each number has a known and equal probability of being selected. Within each IAP area, the sample is then segmented into replicates, or representative subsamples, with each replicate containing sample telephone numbers from each of the 78 IAP areas. Segmenting the sample into replicates allows for the release of telephone numbers over time in a controlled manner.

Updating the NIS Sampling Frame—The set of telephone banks with at least one directory-listed residential telephone number changes over time. As a result, the sampling frame of 1+ working banks also needs to be updated. The recent phenomenon of frequent area-code splits has produced additional changes to the sampling frame. The GENESYS database reflects those changes in a quarterly update. Marketing Systems Group (MSG) has developed a separate sampling frame for each IAP area. Quarterly, the database is examined to determine whether currently included banks should be assigned to different IAP areas and to assign newly included banks to IAP areas. The rules for assignment are the same as in the initial definitions of the IAP areas. Once all modifications have been made to the GENESYS database, a number of checks ensure that all changes have been applied correctly and that the new database produces samples that are consistent with those produced prior to the changes. These checks compare the number of active banks and RDD-selectable lines in each IAP area before and after the update. In parallel, the actual exchanges assigned to each IAP area before and after the update are compared. Small changes are expected – new banks are put into service as new numbers are assigned. In the event of a major discrepancy in any of these checks, MSG is notified of the difference and asked to provide documentation of the reasons for the change.

Forming NIS Sample Replicates—The total size of the initial sample for an IAP area is calculated according to the formula:

$$\text{Total Sample Size} = (1.5)T/(AC),$$

where:

T is the quarterly target number of completed interviews for the IAP area (this target number of completes ranges from 101 to 129);

- A is the proportion of telephone numbers that remain after identifiable business and nonworking numbers have been removed (as discussed below); and
- C is the proportion of telephone numbers sent to the interviewers in the telephone center that result in a completed interview.

In the formula, A and C are specific to the IAP area, and they are adjusted each quarter, taking into account the results from previous quarters. The target, T, may also reflect the results in the previous quarters; for example, if the three previous quarters have not produced their target total of completes, T is raised accordingly. The factor 1.5 allows for variation in actual performance among IAP areas and among quarters.

The total sample selected is then randomly divided into 26 replicates; the first 24 are equal in size, and the last 2 are one-half that size. This procedure permits smoother release of the sample (at the rate of one or two replicates per week) for each IAP area separately, as needed. Toward the end of the quarter, the half-size replicates allow tighter control over the total amount of sample released. The aim is to produce an even distribution of work in the telephone center over the course of a quarter and to give all cases an equal probability of being completed.

Removing Business and Nonworking Numbers—In a traditional RDD survey, all sampled telephone numbers are given to interviewers for dialing. Because over one-half of all selected telephone numbers are businesses or are unassigned, a large part of the interviewers' efforts may be directed simply to identifying and removing these numbers from the active sample. MSG has produced companion products to their GENESYS Sampling System that can quickly and accurately reduce the size of this task.

First, the selected sample is matched against a GENESYS data file that contains telephone numbers that are directory-listed in a business yellow pages and are not directory-listed in a residential white pages. Any business numbers so identified are removed from the sample.

Second, numbers listed in residential white pages are identified and temporarily set aside.

Third, a hardware system, GENESYS-ID Plus, screens the remaining sample to remove a portion of the nonworking numbers. (The GENESYS-ID Plus system was used for Pretest II and the main survey. GENESYS-ID, the precursor to GENESYS-ID Plus, was used for Pretest I.) Using personal computers with special hardware and software, this system (the "autodialer") automatically dials the telephone numbers to detect nonworking numbers. This is indicated by the familiar tri-tone signal for out-of-service numbers, by an extended period of silence, or by continuous noise on the line. If the telephone number being dialed starts to ring, GENESYS-ID Plus hangs up immediately. (Fewer than 6% of the numbers dialed actually ring at the receiving end.) To further reduce the chance of annoyance if a residential number rings, the white pages directory-listed numbers identified in step two are not dialed, and the GENESYS-ID Plus equipment is operated only during daytime hours on weekdays.

Finally, the residential white pages directory-listed numbers are combined with those that were not removed by the autodialers to produce the sample for the telephone centers. Together these steps cull out approximately 35% of the sampled lines in the NIS sample.

Obtaining Addresses for Advance Letters—To obtain addresses that correspond to telephone numbers in the sample, the numbers for each replicate are sent to a company that provides this

matching service. This computerized name-and-address-locating service uses a database of over 160 million residential and business telephone numbers, including unpublished telephone numbers. In some instances, by customer preference, a listing may not contain a street address. The resulting file contains both numbers with and without listing matches. Matched listings contain a business or residential identifier.

“Do Not Call” Requests—The NIS maintains a file containing telephone numbers of people who have requested that they not be called. Each quarter’s sample is compared with this file, and numbers in the “Do Not Call List” are not included in the quarterly sample of numbers loaded into the CATI system.

Duplicate Telephone Numbers—Because of the repeated quarterly selection of sample in each IAP area, it is possible that some telephone numbers will be selected for the NIS more than once. To avoid respondent problems created by recontacts for the same survey, a further step of processing unduplicates the sample numbers selected for the NIS. Each complete replicate sample file is compared with all sample files released during the previous quarters. Detailed records are kept of all area code splits to ensure accurate unduplication.

Similarly, because of the repeated quarterly selection of NIS sample in each IAP area, some telephone numbers were selected more than once over the course of the National Survey of CSHCN data collection period. Such numbers were not contacted a second time for the National Survey of CSHCN. Instead, these cases were automatically finalized. Response rates reflect the final disposition of a telephone line from its original sampling.

National Survey of CSHCN Sample Design and Allocation

The number of CSHCN required to be selected in each IAP area was determined by allocating the total of 750 children in the state to each IAP area within the state in proportion to the total number of households with CSHCN in the IAP area. Based on this allocation, the number of households that needed to be screened in each IAP area were calculated using the expected proportion of households with children in the eligible age range and having special health care needs in the IAP area. Original state-level estimates of the proportion of households with age-eligible children were obtained from the CPS and applied to all IAP areas within a state. These initial estimates were replaced with actual IAP area-specific age-eligibility rates experienced in early National Survey of CSHCN replicates. These rates were continually updated throughout the data collection period. The original estimate of the proportion of households with CSHCN was based on the 1994 National Health Interview Survey—Disability Supplement and was applied to all IAP areas. As with the age-eligibility estimates, this initial estimate was replaced with actual IAP area-specific special-needs eligibility rates experienced in early National Survey of CSHCN replicates. These rates were also updated throughout the data collection period.

The number of telephone numbers that needed to be called was then computed, using the expected working residential telephone number rate. The number of telephone numbers drawn was increased to compensate for a degree of nonresponse, given the assumption that not all respondents would agree to participate.

A random subsample of the required number of telephone numbers for the National Survey of CSHCN in each IAP area was selected from the NIS sample. These numbers were

called in an attempt to identify households and to establish study eligibility in those households. Any household with at least one child less than 18 years of age was considered eligible. One child with special health care needs and/or one child without special health care needs were then selected at random from each household that had such children. As indicated earlier, if a household contained both children with special health care needs and children without special health care needs, then one child was selected at random from each group. That is, in some households, two children were sampled. The selection of the sample was spread over six quarters of NIS data collection. The split of the total sample across quarters varied across IAP areas.

Sampling Weights

To produce population-based estimates, each respondent household and child for whom complete data were available was assigned a sampling weight. These sampling weights compensate for varying probabilities of selection of households and children because of stratification by IAP area and clustering of children within households. Also, the weights are needed to account for nonresponding households and for noncoverage of households without telephones (i.e., only households with telephones were included in the sampling frame).

The sampling weight combines (1) the IAP area base weight, which reflects the probability of selecting the household telephone number; (2) an adjustment for households with multiple telephone numbers; and (3) adjustments for unit nonresponse at various phases of identification and data collection. The method of determining the overall weight for each respondent household and child in the survey is described below.

Three weights were determined. The first weight is the household weight, which is used for the estimation of population values relating to household characteristics and the analysis of household variables. The second weight is the child screener weight. This weight is attached to all of the children in a selected household. The third weight is the child interview weight and is attached to selected children in each household for whom complete data are available.

Household Weight

Base Sampling Weight—As mentioned, a sample of telephone numbers was selected in each IAP area, spread over six quarters of NIS data collection. In the NIS, an independent sample of telephone numbers is selected each quarter. A telephone number could have been selected for the National Survey of CSHCN in any of the six quarters of the data collection period. Once a telephone number was selected, it was not selected again for data collection in subsequent quarters. To compute the base sampling weight, the overall probability of selection considering the probabilities of selection in the different quarters was determined.

Let the number of quarters over which the total sample is selected be q (i.e., 6, since the sample was selected over six quarters). Let p denote the overall probability of selection of the telephone number of the household. We have $p = \sum_{i=1}^q p_i$ where p_i is the probability of selecting the telephone number in the i th quarter. We have

$$p_i = \prod_{j=1}^i (1 - p_{j-1}) \frac{n_i}{N_i}$$

Taking $p_0 = 0$, we have $p_1 = \frac{n_1}{N_1}$ for the first quarter,

$$p_2 = (1 - p_1) \frac{n_2}{N_2}$$

for the second quarter,

$$p_3 = (1 - p_1)(1 - p_2) \frac{n_3}{N_3}$$

for the third quarter, and so forth for each of the remaining quarters.

The base sampling weight for a household in a particular IAP area is given by $w = \frac{1}{p}$.

Generally, this weight is the same for all households within an IAP area.

Because the selection of telephone numbers uses simple random sampling, the probability of selection in each IAP area in each quarter is simply the number of telephone numbers selected divided by the total number of telephone numbers available for selection.

Households with Multiple Telephone Lines—The base sampling weight of eligible households that have multiple voice-use telephone lines was adjusted to compensate for the higher probability of selection of these households. The adjustment divides the base sampling weight by the number of telephone lines in that household.

Let t_k denote the number of telephone lines in the k th household in an IAP area. The adjusted base sampling weight for that household is given by $w_k = \frac{w}{t_k}$. If the household had only one telephone line, then the adjusted weight is the same as the base sampling weight.

Unit Nonresponse Adjustment 1 (Residential Status Unknown)—When a selected telephone number is called, three results are possible: (1) the number called is a household, (2) the number called is not a working residential number (it could be a business number or non-working number), or (3) there is nonresponse to the screening attempt, and therefore the status of the telephone number is unknown. In the National Survey of CSHCN, several call attempts were made before a number was assigned unknown status. The method of adjusting the base sampling weight to account for possible residential numbers in the third category described above is the same as the method used in the National Immunization Survey. This method is described in detail in the *1994 National Immunization Survey Methodology Report*. In the NIS, information external to the survey is used to reallocate these unknown numbers to either residential or nonresidential numbers.

When we call n telephone numbers in an IAP area, let the number of telephone numbers in each of the three categories mentioned above be n_1 , n_2 , and n_3 , respectively. The first nonresponse adjustment factor is $A_1 = \frac{n_1 + \hat{n}_{31}}{n_1}$ where \hat{n}_{31} is the estimated number of households among n_3 , the “status unknown” category. The procedure for estimating the number of households in the unknown category is based on a study conducted in 1994 in which telephone company business offices were asked to report on the status of a sample of category 3 telephone numbers (Shapiro et al., 1995). The results of the study showed that the proportion of residential numbers varies according to the region, whether the telephone number was directory-listed, and the type of non-contact (e.g., ring-no-answer versus answering machine). Therefore, the nonresponse adjustment factor within each IAP area was calculated for a set of numbers defined by region, disposition code, and whether the number was directory-listed. To keep the notation simple, the adjustment factor is denoted by A_1 , although it could be different for different households within each IAP area. The nonresponse-adjusted base sampling weight after nonresponse adjustment 1 for the k th household in an IAP area is given by $A_1 w_k$. The adjusted weight is for all known households.

Unit Nonresponse Adjustment 2 (Households of Unknown Age-Eligibility)—A second form of nonresponse may occur because a household does not complete the screener questions relating to the age-eligibility of the household for the survey. Therefore, for these telephone numbers identified as belonging to a household, there is no determination of eligibility. A description of the adjustment for this form of nonresponse follows.

Let the number of households screened to be eligible out of the n_1 households contacted be q_1 . Let the number of households screened to be ineligible be q_2 . Let q_3 denote the number of households that are nonrespondents to the eligibility question. We have $n_1 = q_1 + q_2 + q_3$. The nonresponse adjustment to the sampling weight to account for not being able to determine the eligibility of q_3 households is given by

$$A_2 = \frac{\sum_{k=1}^{n_1} A_1 w_k}{\sum_{k=1}^{q_1+q_2} A_1 w_k}$$

The nonresponse-adjusted base sampling weight after nonresponse adjustment 2 is given by $A_2 A_1 w_k$. The adjusted weight is determined for all eligible households.

Unit Nonresponse Adjustment 3 (Nonresponse by Age-Eligible Households)—An age-eligible household was considered a nonrespondent if data regarding the special needs status of children in the household were not obtained. The weights of other responding households were increased to account for this nonresponse. These adjustments were made within an IAP area.

Let the number of households in which a screener was not completed be q_{r1} out of the total of q_1 households. The nonresponse adjustment factor is

$$A_3 = \frac{\sum_{k=1}^{q_1} A_1 A_2 w_k}{\sum_{k=1}^{q_{r1}} A_1 A_2 w_k}$$

The final nonresponse-adjusted base sampling weight is the product of the adjustments and weights described thus far. The adjusted weight is $w_{ak} = A_1 A_2 A_3 w_k$. This adjusted household weight is determined for all eligible households in which a screening interview was completed.

Poststratification Weight Adjustment including Adjustment for Noncoverage of Nontelephone Households—Poststratification separates the actual sample into cells, or strata, defined by characteristics that are related to response propensities and to characteristics of interest in the survey. Then, the weighted distribution of completed interviews over the cells is brought into agreement with a corresponding set of population totals by adjusting the weight using a ratio estimator. This weighting adjustment is intended to compensate for noncoverage and for differential unit nonresponse. Poststratification adjustment of the weights may also reduce the variance of the estimates if there is homogeneity within poststrata with respect to the characteristics of interest.

The poststratification variables that were used for dividing the National Survey of CSHCN sample into poststratification cells for adjustment of the household weights were the following:

1. Number of children less than 18 years of age;
2. Race and ethnicity of the children;
3. Mother's education;
4. Income; and
5. Telephone service status.

The number of children under the age of 18 was chosen as a poststratification variable because it was conjectured that the number of children within a household might have an impact on response propensities. For example, parents with more children may have less time available for the survey. In addition, parents with more children may have fewer resources available to care for each child, and parents with fewer resources may be less likely to provide preventive health care for their children (Jensen and Ahlburg, 1997; Human Resources Development Canada, 2001).

Race and ethnicity was included in the poststratification adjustment because it is well documented that Hispanic children, non-Hispanic black children, and other minority children suffer greater health disparities and face more barriers to health care than Whites (Harvard Medical School, 2002; AHRQ, 2002). Research also suggests that response propensity may differ for certain racial and ethnic groups (Groves & Couper, 1998; Sweet, 1990).

Mother's education was included in the poststratification adjustment because RDD studies tend to disproportionately represent higher-educated groups (Ellis & Krosnick, 1999). Based on unweighted proportions, the National Survey of CSHCN suffered similarly. Because it was suspected that mother's education may also be related to child health, a decision was made to poststratify on this dimension.

Income was chosen as a poststratification variable because it is related to health care outcomes, including insurance coverage. Also, research indicates that survey response is related to household income; low-income groups are often underrepresented in telephone surveys because of difficulties contacting low-income households by telephone (Brehm, 1997).

Finally, because RDD studies are unable to capture households that lack telephone service at the time of interview, poststratification included an indicator of any interruption in telephone service. Prior research indicates that adjusting the weights of households that report an interruption in telephone service within the past year can reduce the bias associated with this type of noncoverage (Frankel et al., 2000; Keeter, 1995; Brick et al., 1996).

The sample of interviewed households was divided into cells representing more detailed categories of each variable listed above. Poststratification adjustments were not done in each cell formed by the cross-classification of the different categories of the stratification variables because control totals for each cell were not available. Only the marginal population control totals were determined. Therefore, for adjusting the weights, raking (Lohr, 1999) was used. Raking is a poststratification method that can be used when only marginal control totals are known.

Missing values for variables required for poststratification of households in the sample were imputed, either by Weighted Sequential Hotdeck or through the use of models. Details regarding the imputation appear in Table 12.

<< INSERT TABLE 12 ABOUT HERE >>

The number of households in each state in 2001 was estimated by taking 2000 decennial Census totals and projecting these totals to 2001 using data from the Current Population Survey. The distribution of households by the number of children under 18 was obtained by averaging the estimates from the 1999, 2000, and 2001 CPS. This distribution was then applied to the previously established control total for each state, providing the control totals for each household-size category. Similarly the distributions of households by race/ethnicity, income, and mother's education were determined in the same manner from the CPS and then applied to the total number of households.

Establishing control totals required to adjust the weights for noncoverage of nontelephone households was done as follows. First, the CPS estimate of the percentage of nontelephone households in the state was obtained. This proportion was applied to the known number of households to establish the number of households with and without telephones in the state. Using National Survey of CSHCN data, the weighted percentage of telephone households with a service interruption within the past year was determined. This percentage was then applied to the known number of telephone households (from the CPS) to give the number of households in the state with an interruption in service. The number of telephone households without interruptions in telephone service formed one control total. The number of households without telephones plus the number of telephone households with interruptions in service formed the other control total. The weights of interviewed households in the sample without interruptions in service were raked such that the sum of the weights equaled the known number of telephone households without interruptions in telephone service. Similarly, the weights of telephone households with interruptions in telephone service were raked in the sample such that the sum of the weights agreed with the sum of the number of nontelephone households and the number of telephone households with interruptions in telephone service. As indicated earlier,

Table 12. Variables with imputed values

Variable	Number of Missing Values	Imputation Method
Age	278	Weighted Sequential Hotdeck
Gender	630	Weighted Sequential Hotdeck
Race	3,059	Stage 1: Majority Rule within Household Stage 2: Weighted Sequential Hotdeck
Hispanic Origin	1,624	Stage 1: Majority Rule within Household Stage 2: Weighted Sequential Hotdeck
Number of Telephone Lines	2,613	Unweighted Sequential Hotdeck
Interrupted Telephone Service	3,241	Majority Rule within Dataset
Mother's Residency	6,941	Stage 1: Data Copied from Other Sampled Child within Household if Applicable Stage 2: Weighted Sequential Hotdeck
Mother's Education	7,894	Stage 1: Data Copied from Other Sampled Child within Household if Applicable Stage 2: Weighted Sequential Hotdeck
Household Income	23,323	Combination of Weighted Sequential Hotdeck and Regression Modeling

NOTE: Number missing for age, gender, race, and Hispanic origin are from a total of 373,055 screened children. Number missing for number of telephone lines, interrupted telephone service, and household income are from a total of 196,888 screened households. Number missing for mother's residency is from a total of 215,163 interviewed children. Number missing for mother's education is from a total of 205,388 interviewed children with a resident mother or where residency was also missing.

these weight adjustments were done through raking, such that the aggregated weights agreed with the totals in other margins.

The poststratified weight is the final household weight used for the estimation and analysis of household-level variables. This weight for the k th household in an IAP area will be denoted by w_{fk} where f stands for the final weight. Final household weights appear in the National Survey of CSHCN Household Data File, denoted by WEIGHT_H. Household weighting detail by state appears in Table 13.

<< INSERT TABLE 13 ABOUT HERE >>

Child Screener Weight

To determine the child screener weight, the final household weight w_{fk} was initially used. This weight was attached to all of the children in a selected household, including children with special health care needs.

The next step was to adjust these weights such that the sum of the weights over all children screened agreed with known marginal control totals for the following variables, which were drawn from the CPS as described previously:

1. Number of children less than 18 years of age in the household;
2. Sex of the child;
3. Age of the child;
4. Race and ethnicity of the child;
5. Mother's education;
6. Household income; and
7. Telephone service status.

The poststratification weight adjustment was again done through raking, using the control totals. The final raked child screener weight is denoted by w_{fkj} . This is the weight for the j th child in the k th household. This weight is used for producing child-level estimates using data collected at the time of screening for special health care needs. For example, this weight is used to estimate the number of children in the population with special health care needs and without special health care needs based on the screener sample. Final child-level screener weights appear in the National Survey of CSHCN Screener Data File, denoted by WEIGHT_S. Child screener weighting detail by state appears in Table 14.

<< INSERT TABLE 14 ABOUT HERE >>

Child Interview Weight

Let the number of children with special health care needs in the k th household in an IAP area be N_{ks} and the number of children in the same household without special health care needs be $N_{k\bar{s}}$. The total number of children in the household is $N_k = N_{k\bar{s}} + N_{ks}$. Not all households contain both types of children.

Table 13: Summary statistics for household weights by state

Location	Unweighted Sample Size	Minimum Weight	Maximum Weight	Mean Weight	Median Weight	Sum of Weights
Alabama	3,843	21.6	826.9	164.8	136.0	633,444
Alaska	4,333	2.3	98.6	22.2	18.1	96,262
Arizona	4,276	19.0	830.9	165.2	143.1	706,420
Arkansas	3,655	16.3	515.2	103.0	93.4	376,447
California	4,967	89.3	4,826.8	939.6	739.6	4,666,965
Colorado	4,129	16.0	733.1	146.5	126.6	605,002
Connecticut	3,469	16.5	581.9	131.7	110.9	456,829
Delaware	3,339	3.0	165.9	32.4	29.2	108,184
D. C.	4,048	1.0	78.4	15.0	12.3	60,669
Florida	4,135	37.2	2,610.6	496.3	404.9	2,052,306
Georgia	4,077	34.6	1,499.6	296.7	246.2	1,209,738
Hawaii	4,976	5.5	156.5	31.0	26.8	154,238
Idaho	4,049	5.4	236.5	46.4	40.5	187,960
Illinois	4,027	36.2	2,362.6	418.0	305.1	1,683,295
Indiana	3,553	27.4	1,186.0	237.1	222.7	842,524
Iowa	3,948	22.0	427.9	97.3	85.2	384,040
Kansas	3,400	15.0	533.3	109.5	100.3	372,452
Kentucky	3,412	18.0	837.8	166.3	143.9	567,572
Louisiana	3,235	26.5	1,008.2	201.5	170.6	651,799
Maine	3,124	10.1	163.8	53.6	48.8	167,301
Maryland	3,345	21.3	929.5	224.7	216.1	751,470
Massachusetts	3,434	27.2	1,242.1	237.3	179.3	814,749
Michigan	3,485	60.4	1,782.9	389.1	321.6	1,355,895
Minnesota	3,612	29.4	934.4	184.8	147.7	667,350
Mississippi	4,005	13.2	532.4	104.6	85.8	419,057
Missouri	6,742	15.2	572.3	114.3	102.6	770,775
Montana	4,006	5.5	122.1	30.1	27.3	120,562
Nebraska	3,777	5.5	305.7	61.4	55.6	231,836
Nevada	4,553	8.9	319.0	63.1	55.6	287,274
New Hampshire	3,320	7.1	201.8	51.3	40.7	170,341
New Jersey	4,107	5.3	1,405.4	278.2	238.8	1,142,576
New Mexico	4,170	6.3	324.7	64.0	52.7	266,856
New York	4,308	67.3	2,906.7	579.0	489.7	2,494,162
North Carolina	3,624	62.5	1,621.0	312.4	268.1	1,132,102
North Dakota	3,949	3.3	106.0	21.1	19.8	83,510
Ohio	3,597	78.4	1,713.2	428.0	368.6	1,539,570
Oklahoma	3,589	18.8	677.4	134.7	115.9	483,309
Oregon	3,650	16.4	640.8	124.8	106.5	455,481
Pennsylvania	3,874	64.9	2,026.9	404.3	373.0	1,566,146
Rhode Island	3,378	3.5	202.4	40.2	31.6	135,746
South Carolina	3,647	12.5	780.0	155.9	136.4	568,473
South Dakota	4,120	4.4	123.6	24.7	21.8	101,639
Tennessee	3,567	26.4	1,146.6	224.1	191.6	799,368
Texas	4,088	65.2	3,824.9	760.9	637.7	3,110,501
Utah	3,896	12.5	296.7	85.1	79.3	331,674
Vermont	3,312	3.8	124.2	24.5	24.2	81,301
Virginia	3,288	47.0	1,517.9	299.8	266.1	985,680
Washington	3,517	21.1	1,168.5	233.0	209.9	819,364
West Virginia	3,441	6.1	355.7	67.4	53.7	231,759
Wisconsin	3,642	43.8	931.6	195.7	173.4	712,887
Wyoming	3,850	3.0	73.6	17.6	17.8	67,694

Table 13

Table 14: Summary statistics for child-level screener weights by state

Location	Unweighted Sample Size	Minimum Weight	Maximum Weight	Mean Weight	Median Weight	Sum of Weights
Alabama	6,904	20.3	821.5	164.0	133.9	1,132,020
Alaska	8,548	1.9	115.0	22.7	18.8	194,247
Arizona	8,542	16.0	924.6	168.0	145.1	1,434,674
Arkansas	6,616	13.2	522.6	104.1	90.7	688,509
California	9,662	73.3	4943.9	981.7	778.9	9,484,792
Colorado	7,864	13.7	753.9	145.0	125.0	1,140,139
Connecticut	6,411	16.6	563.6	133.5	110.8	855,619
Delaware	6,181	2.9	167.6	32.3	27.9	199,440
D. C.	7,400	1.0	78.0	15.5	12.1	114,868
Florida	7,572	34.1	2521.2	498.6	391.1	3,775,238
Georgia	7,479	27.4	1674.7	299.4	251.0	2,238,948
Hawaii	9,382	2.6	179.1	31.8	29.7	298,093
Idaho	8,366	5.2	226.0	45.2	39.8	378,378
Illinois	7,761	33.4	2713.4	423.6	313.7	3,287,379
Indiana	6,744	22.8	1180.4	235.8	224.3	1,590,441
Iowa	7,766	19.6	472.8	94.8	84.2	735,994
Kansas	6,517	15.1	510.0	110.6	101.7	720,762
Kentucky	6,032	19.2	962.7	165.8	144.0	1,000,165
Louisiana	5,964	22.0	1033.8	204.5	166.3	1,219,590
Maine	5,646	9.6	163.0	53.3	48.7	300,788
Maryland	6,161	21.0	1055.1	225.1	207.5	1,386,935
Massachusetts	6,411	30.5	1240.8	237.5	177.3	1,522,314
Michigan	6,637	60.8	1966.8	394.0	328.9	2,615,150
Minnesota	6,946	25.2	940.0	188.0	151.7	1,305,743
Mississippi	7,374	10.7	535.9	105.6	83.1	778,905
Missouri	12,824	13.6	562.8	112.6	99.0	1,443,854
Montana	7,652	5.0	141.5	30.3	26.6	231,520
Nebraska	7,420	5.0	259.7	61.1	52.2	453,494
Nevada	8,911	7.3	314.0	62.7	52.5	558,465
New Hampshire	6,127	6.1	257.3	51.4	41.3	314,751
New Jersey	7,506	5.0	1470.5	283.9	236.9	2,130,620
New Mexico	8,110	3.7	520.2	63.9	43.7	517,933
New York	8,030	75.6	2958.6	591.8	504.1	4,752,409
North Carolina	6,432	51.0	1628.7	314.0	257.7	2,019,342
North Dakota	7,527	3.2	128.0	21.2	19.4	159,507
Ohio	6,844	65.8	2058.1	423.8	361.8	2,900,609
Oklahoma	6,684	17.3	743.5	134.7	112.9	900,135
Oregon	6,905	19.0	625.6	125.3	107.1	864,911
Pennsylvania	7,322	62.9	2005.9	401.8	360.9	2,941,751
Rhode Island	6,134	3.5	185.0	40.9	35.0	251,131
South Carolina	6,662	9.4	732.0	153.4	133.9	1,022,128
South Dakota	8,213	4.4	126.5	24.8	21.7	203,539
Tennessee	6,338	26.3	1126.7	224.8	195.8	1,424,737
Texas	7,848	57.7	3885.0	770.7	637.6	6,048,116
Utah	8,850	12.2	253.5	82.8	78.8	732,952
Vermont	6,064	3.5	124.8	24.5	23.4	148,562
Virginia	5,826	41.8	1518.3	304.3	264.6	1,773,139
Washington	6,629	21.2	1169.2	234.4	212.8	1,553,745
West Virginia	6,034	5.5	383.5	65.9	50.1	397,797
Wisconsin	6,948	40.2	987.7	198.8	175.3	1,381,019
Wyoming	7,448	2.7	62.1	17.2	18.2	128,330

Table 14

One child of each type was selected from every household with such children. That is, in households in which only CSHCN were present, one child with special health care needs was selected at random. This was also the case for households having only children without special health care needs. In households where both types of children were present, two children (one from each group) were selected. The sampling weight for a selected child with special health care needs is $w_k^{cs} = w_{fk} N_{ks}$. That is, the final household weight is multiplied by the number of CSHCN in a household. Similarly, the weight for a selected child without special health care needs is given by $w_k^{c\bar{s}} = w_{fk} N_{k\bar{s}}$.

Child-Level Interview Nonresponse Adjustment—Data were not obtained for all children selected for interview. Therefore, the weights were adjusted using those children for whom data were available to account for those children for whom no data were collected. The nonresponse adjustment factor A_4 within an IAP area was computed as follows.

Let the number of households containing children with special health care needs out of the q_{r1} responding households be q_{r1l} and the number of households without special health care needs children be q_{r1o} . Note that $q_{r1l} + q_{r1o} \neq q_{r1}$ because households may contain both types of children.

Let the number of households in which special-needs interviews are completed among the q_{r1l} households be q_{r1l}^* . Similarly, let the number of households in which interviews are completed regarding children without special needs be q_{r1o}^* . The nonresponse adjustment factor for the interview nonresponse by children with special health care needs is given by

$$A_4^s = \frac{\sum_{k=1}^{q_{r1l}} w_{fk} N_{ks}}{\sum_{k=1}^{q_{r1l}^*} w_{fk} N_{ks}}$$

The numerator gives the estimated number of CSHCN based on all the responding screener households. The denominator gives the estimated number of CSHCN based on the households in which an interview was completed. Similarly, the adjustment factor for adjusting the weights of children without special health care needs is

$$A_4^{\bar{s}} = \frac{\sum_{k=1}^{q_{r1o}} w_{fk} N_{k\bar{s}}}{\sum_{k=1}^{q_{r1o}^*} w_{fk} N_{k\bar{s}}}$$

The nonresponse adjusted sampling weights for responding children are $w_{ak}^{cs} = A_4^s w_k^{cs}$ and $w_{ak}^{c\bar{s}} = A_4^{\bar{s}} w_k^{c\bar{s}}$.

Poststratification Weight Adjustment for Child Interview Weights—The two weights given above, one for children with special health care needs and the other for children without special health care needs, were adjusted through raking such that the sum of the weights over all children agreed with all control totals used for child screener weights and with the estimated number of children with and without special health care needs obtained using the final child screener weight.

The final raked weights are denoted by w_{fjkj}^{cs} and $w_{fjkj}^{\bar{cs}}$. These weights are used for the analysis of child-level variables and appear in the CSHCN Interview data file and the Insurance Analysis data file, denoted by WEIGHT_I. Since these two files are child-level data files, this single variable contains the final child-level weight for both children with and without special needs. Child interview weighting detail for CSHCN by state appears in Table 15. Weighting detail for children without special health care needs appears in Table 16.

<< INSERT TABLES 15 AND 16 ABOUT HERE >>

Trimming Weights

In sample surveys, very large or extreme sampling weights are often truncated, or “trimmed,” as large variation in weights can result in large sampling variances of the survey estimates. This is especially true if the sampling weights are not correlated with the values or characteristics of interest. In such cases, the few observations having very large weights may unduly contribute to the overall estimate. Sometimes, large variation in weights is a result of the design in which the probabilities of selection of sampling units are positively correlated with values of observations on those units. Large weights can also be a result of sample selection procedures and adjustments for unit nonresponse.

It should be noted that a trimming procedure, while reducing the variance of the estimates, may result in increased bias in the estimates. The objective of trimming is to reduce the variance such that the reduction more than compensates for the increase in bias. Therefore, trimming is usually minimized as much as possible.

No strict rules or procedures for defining extreme weights or for trimming such weights exist, and various methods of weight trimming are practiced. In the case of some surveys that employ weighting, the size of the nonresponse and other adjustments to the base sampling weights are restricted, to avoid large final weights altogether. Other surveys examine the distribution of the final weights to identify extreme weights and propose trimming rules. This method is more common because it is easier to identify extreme weights by looking at the entire distribution of the weights.

For the National Survey of CSHCN, the method of examining the distribution of the final weights to identify extreme weights before trimming was used. Restricting the size of the nonresponse adjustments was not attempted because the unit nonresponse adjustments, generally, were not large. Alternatively, rather than restricting the size of the adjustments, the weights could have been trimmed after each adjustment. To do so, rules for determining outlier weights would have had to be specified at each stage. As mentioned earlier, identification of outlier weights in the distribution of final weights is easier than attempting to identify such outliers at each weighting stage, particularly since some large national weights in the National Survey of CSHCN result from the state-level design of the sample.

Table 15: Summary statistics for child-level interview weights for children with special health care needs, by state

Location	Unweighted Sample Size	Minimum Weight	Maximum Weight	Mean Weight	Median Weight	Sum of Weights
Alabama	749	20.1	1,411.8	202.9	147.9	152,002
Alaska	746	2.4	190.4	27.3	21.3	20,370
Arizona	751	17.4	1,782.1	210.4	156.4	157,991
Arkansas	749	22.5	911.8	128.0	99.0	95,907
California	759	82.1	10,375.7	1,280.9	977.9	972,201
Colorado	744	14.9	1,339.2	178.9	141.1	133,069
Connecticut	742	25.3	1,061.1	161.8	118.2	120,033
Delaware	742	5.6	315.5	41.3	32.5	30,653
D. C.	748	2.1	157.2	21.3	14.4	15,927
Florida	750	66.8	4,538.3	651.8	460.1	488,854
Georgia	748	37.5	2,999.2	380.4	290.6	284,533
Hawaii	747	2.3	330.9	40.3	29.0	30,132
Idaho	745	5.5	402.7	57.1	45.3	42,563
Illinois	745	55.6	4,580.4	517.1	331.4	385,269
Indiana	747	39.3	2,132.1	301.0	246.8	224,877
Iowa	751	26.6	655.2	120.5	96.8	90,507
Kansas	748	24.1	965.5	143.4	114.0	107,234
Kentucky	745	26.4	1,361.1	210.4	164.5	156,767
Louisiana	749	21.3	1,922.4	254.4	184.7	190,570
Maine	742	10.2	347.3	63.1	51.7	46,808
Maryland	750	23.5	1,917.2	284.0	236.7	213,005
Massachusetts	744	52.8	2,231.6	299.2	224.0	222,606
Michigan	748	70.7	3,364.9	486.4	340.9	363,853
Minnesota	749	28.1	1,696.9	217.3	152.6	162,756
Mississippi	743	11.1	1,003.5	134.4	89.7	99,866
Missouri	1,493	9.4	1,618.4	146.3	109.2	218,400
Montana	742	5.5	223.5	36.7	27.9	27,230
Nebraska	747	12.0	548.5	78.3	59.2	58,494
Nevada	747	7.6	598.8	80.6	61.0	60,225
New Hampshire	750	8.2	451.6	63.8	48.5	47,814
New Jersey	744	11.6	2,567.5	370.5	254.7	275,617
New Mexico	751	6.8	924.3	75.8	47.2	56,927
New York	748	114.1	5,411.5	752.1	596.0	562,536
North Carolina	739	49.9	2,756.4	380.6	277.2	281,233
North Dakota	746	5.0	174.2	26.5	20.8	19,784
Ohio	766	100.8	3,760.6	529.5	406.1	405,609
Oklahoma	745	16.6	1,225.3	176.6	123.4	131,586
Oregon	745	24.6	1,192.5	154.9	115.0	115,367
Pennsylvania	748	87.7	3,530.0	511.7	410.6	382,720
Rhode Island	750	5.2	276.2	48.6	38.4	36,413
South Carolina	745	19.2	905.9	184.7	148.8	137,612
South Dakota	741	6.9	174.7	31.1	25.2	23,075
Tennessee	747	37.2	1,832.8	267.6	210.8	199,913
Texas	751	155.0	7,082.6	957.4	700.3	719,014
Utah	742	21.0	749.4	110.2	85.3	81,785
Vermont	748	3.3	212.0	31.0	25.8	23,167
Virginia	747	50.9	1,785.9	366.5	289.7	273,771
Washington	756	23.9	1,915.6	288.0	243.5	217,706
West Virginia	748	7.8	588.0	88.6	55.4	66,240
Wisconsin	750	38.9	1,699.6	247.6	187.9	185,698
Wyoming	749	2.9	145.5	21.6	19.0	16,176

Table 15

Table 16: Summary statistics for child-level interview weights for children without special health care needs, by state

Location	Unweighted Sample Size	Minimum Weight	Maximum Weight	Mean Weight	Median Weight	Sum of Weights
Alabama	3,493	23.3	1,458.3	280.6	219.2	980,018
Alaska	4,034	3.0	238.9	43.1	33.1	173,824
Arizona	3,948	21.9	1,861.6	323.4	235.4	1,276,683
Arkansas	3,297	12.2	945.5	179.7	135.0	592,602
California	4,661	66.3	10,510.7	1,826.3	1,284.5	8,512,591
Colorado	3,818	12.6	1,360.0	263.8	205.0	1,007,070
Connecticut	3,148	16.1	1,159.4	233.7	202.6	735,586
Delaware	2,977	2.6	315.6	56.7	40.6	168,787
D. C.	3,641	0.8	163.4	27.2	17.9	98,941
Florida	3,744	57.1	4,866.6	877.8	671.6	3,286,384
Georgia	3,690	25.7	3,168.6	529.7	361.2	1,954,415
Hawaii	4,633	2.3	404.4	57.8	33.8	267,961
Idaho	3,774	6.5	463.5	89.0	70.3	335,815
Illinois	3,710	30.0	5,204.3	782.2	555.3	2,902,110
Indiana	3,221	20.7	2,143.4	424.0	328.4	1,365,564
Iowa	3,640	22.2	878.4	177.3	153.3	645,487
Kansas	3,036	14.6	987.6	202.1	160.7	613,528
Kentucky	3,015	24.2	1,516.5	279.7	221.7	843,398
Louisiana	2,847	19.0	2,015.7	361.4	259.1	1,029,020
Maine	2,808	14.3	424.7	90.4	75.4	253,980
Maryland	2,968	19.7	2,050.9	395.5	307.9	1,173,930
Massachusetts	3,084	29.7	2,342.1	421.4	302.8	1,299,708
Michigan	3,154	54.4	3,711.5	713.8	537.0	2,251,297
Minnesota	3,331	26.7	1,750.2	343.1	258.3	1,142,987
Mississippi	3,639	8.6	1,086.0	186.6	134.8	679,039
Missouri	3,142	26.1	1,650.6	390.0	310.8	1,225,454
Montana	3,676	5.7	304.7	55.6	44.9	204,290
Nebraska	3,461	9.4	560.9	114.1	93.5	395,000
Nevada	4,243	9.5	620.5	117.4	93.3	498,240
New Hampshire	2,976	8.3	459.2	89.7	70.7	266,937
New Jersey	3,766	4.9	2,745.6	492.6	388.8	1,855,003
New Mexico	3,836	3.3	1,105.5	120.2	77.2	461,006
New York	3,953	74.0	5,411.7	1,059.9	833.6	4,189,873
North Carolina	3,239	52.3	2,846.1	536.6	420.2	1,738,109
North Dakota	3,640	3.4	231.4	38.4	29.9	139,723
Ohio	3,239	81.7	3,953.7	770.3	605.4	2,495,000
Oklahoma	3,219	16.2	1,328.8	238.8	177.9	768,549
Oregon	3,316	18.2	1,209.8	226.0	185.2	749,544
Pennsylvania	3,525	65.1	3,585.4	726.0	580.0	2,559,031
Rhode Island	3,058	3.3	364.7	70.2	53.7	214,718
South Carolina	3,291	8.3	1,338.7	268.8	212.3	884,516
South Dakota	3,847	5.0	229.2	46.9	38.5	180,464
Tennessee	3,199	38.4	1,927.1	382.9	315.8	1,224,824
Texas	3,722	54.9	7,734.3	1,431.8	1,119.6	5,329,102
Utah	3,635	14.1	853.6	179.1	145.7	651,167
Vermont	2,989	3.8	234.6	42.0	31.5	125,395
Virginia	2,903	51.3	2,639.6	516.5	421.4	1,499,368
Washington	3,185	23.3	2,086.4	419.5	336.6	1,336,039
West Virginia	3,061	7.6	681.0	108.3	81.1	331,557
Wisconsin	3,333	46.0	1,759.6	358.6	303.4	1,195,321
Wyoming	3,531	3.0	160.8	31.8	24.1	112,154

Table 16

A decision was made to define a weight as extreme if it exceeded 5 times the mean weight. (The standard deviation of weights was not used to guide trimming because it is affected by extreme weights.) Using the final, poststratified child screener weight as an example, a formal description of the trimming process applied follows. This process occurred for each of the four poststratified weights produced (i.e., household, child screener, interview).

Let w_{jkj} denote the final poststratified sampling weight for the j th child in the sample. Let the number of respondent children in the sample with a final sampling weight be n . We compute the mean of these weights. Let w_m be the mean of these weights. Any weight exceeding the value $5w_m$ is truncated and the weight set equal to $5w_m$.

Typically, once trimming has been done, the weights of those observations with untrimmed weights are increased such that the sum of the new weights equals the sum of the weights before trimming. Assume that we have trimmed k weights. The sum of the original weights is $\sum_{i=1}^n w_{ijkj}$. The sum of the new weights is $\sum_{i=1}^{n-k} w_{ijkj} + k(5w_m)$. We want the two sums to be equal. Therefore, the untrimmed weights are adjusted by a factor which is equal to

$$\frac{\sum_{i=1}^n w_{ijkj} - k(5w_m)}{\sum_{i=1}^{n-k} w_{ijkj}}$$

This adjustment is done as a part of raking the weights such that the sum of the weights agrees with various control totals in the other margins.

National Estimates

The state sampling weights are used to obtain estimates for each state. To obtain national estimates of totals, state estimates should be aggregated. For computing national estimates of ratios (e.g., the proportion of children with special health care needs among all children nationally), the ratio is produced by aggregating the state estimates and dividing this number by the total number of children in the U.S., again by aggregating the state totals.

Standard Errors of Estimates

Because of the complex design of the National Survey of CSHCN, the household records and the child-level screener and interview records have unequal weights. Therefore, statistical software programs that assume simple random sampling will most often compute standard errors that are too small. Tests of statistical hypotheses may then reveal statistically significant differences or associations that are misleading. However, computer programs are available that provide the capability of variance estimation for complex sample designs (e.g., SUDAAN, Stata, WesVar). In order to provide the user with the capability of estimating the complex sample variances for the National Survey of CSHCN data, we have provided stratum identifiers and

primary sampling unit (PSU) codes on the data files. These variables and the sample weights are necessary for the calculation of variances.

It should be noted that the stratum identifiers reported on the data set are not identical to the strata used for drawing the sample. In states with multiple IAP areas, independent samples were selected from each IAP area in proportion to the total number of households with children in each IAP area. Therefore, these IAP areas should be considered strata for variance estimation. However, disclosure of the specific IAP area for each child (even if the code were scrambled) could increase the risk of disclosure of a respondent's identity. For example, the IAP area with the lowest frequency of responses in New Jersey would be readily identifiable as Newark. In the absence of IAP-specific identifiers, data users should use the state identifier (STATE) as the stratum identifier. By using the state identifier rather than the suppressed IAP identifier, the standard errors for national and state estimates with key variables are affected only slightly, and not in a consistent direction. The PSU for the National Survey of CSHCN is the household and is represented on the data sets by the unique household identifier, IDNUMR.

The overall number of persons in this survey is sufficient for most statistical inference purposes. However, analyses of some rare responses and analyses of subclasses can lead to estimators that are unreliable. Small sample sizes used in the variance calculations may also produce unstable estimates of the variances. Consequently, these analyses require that the user pay particular attention to the coefficient of variation for the estimates of means, proportions, and totals.

Standard errors for the National Survey of CSHCN can be obtained using the Taylor-series-approximation method, available in software such as SUDAAN, SAS, and Stata. As noted previously, the state should be identified as the stratum variable and the household should be identified as the primary sampling unit.

The simplifying assumption that PSUs have been sampled with replacement allows most complex survey sample design computer programs to calculate Taylor-series standard errors in a straightforward way. This method requires no recoding of design variables, but is statistically less efficient (and therefore more conservative) than some other methods because the PSU unit is treated as being sampled with replacement within the stratum unit. For SUDAAN, the data file needs to be sorted by stratum (STATE) and PSU (IDNUMR) prior to invoking SUDAAN. The following SUDAAN design statements are used for analyses at the household level:

```
PROC . . . DESIGN = WR;  
  NEST STATE IDNUMR;  
  WEIGHT WEIGHT_H;
```

For analyses of the Screener File data at the child level, replace “WEIGHT_H” with “WEIGHT_S”. For analyses of the CSHCN Interview File or Insurance Analysis File data, replace “WEIGHT_H” with “WEIGHT_I”.

The instructions given above for variance estimation assume that the weights are fixed. That is, in repeated samples of households and children, the weights attached to each child in an IAP area are assumed to be constant. But the final weights are obtained after various adjustments to the base sampling weight. These adjustments depend on the sample selected. Therefore, the variance estimates do not reflect the sampling variability of the weights. Thus, to a certain extent, there is underestimation of variance. In addition, there is a slight overestimation of variance due to the assumption of with-replacement sampling of households when actually

households were selected without replacement. The extent of underestimation depends on the variability in weights in repeated samples. We believe that the underestimation may not be severe, as the sample sizes are large. Also, the weights have been raked to multiple control totals.

It should be noted that other variance estimation procedures are also applicable to the National Survey of CSHCN. Specifically, the jackknife method with replicate weights and the bootstrap resampling method with replicate weights can also be used (via software such as WesVar) to obtain standard errors that fully reflect the impact of the weighting adjustments on standard errors. For the NIS, jackknife variance estimates of vaccination coverage rates were computed, but were found to be very similar to the estimates obtained using Taylor series approximation.

Appendix II

Computer-Assisted Telephone Interview Specifications

Specifications for the telephone interview (including question wording and instructions for skipping questions) will be added when this report is published in 2003. Until such time, these specifications may be found on the NCHS website at:

<http://www.cdc.gov/nchs/slait.htm>

Appendix III

Summary of CATI Instrument Changes

1. On October 23, 2000, the phrase “At this time” was added at the beginning of insurance questions C7Q01, C7Q02, C7Q03, C7Q04, C7Q06, and C7Q07. For example, the wording of question C7Q06 changed from “Is (S.C.) enrolled in a Title 5 program?” to “At this time, is (S.C.) enrolled in a Title 5 program?”

2. On October 26, 2000, the order of the first four questions in Section 7 was changed so that the items regarding private insurance would be first in the series. In addition, the introduction used with the first item was revised and the word “private” was removed from questions C7Q03 and C7Q03A. The first four questions in the original insurance section were:

C7Q01 (7.1)—The next questions are about all types of health insurance and health care coverage (S.C.) may have. Is (S.C.) covered by Medicaid, a health insurance program for persons with certain income levels and persons with disabilities? [FILL IF APPLICABLE: In this state, the program is sometimes called [STATE PROGRAM].

C7Q02 (7.2)—Is (S.C.) covered by {S-CHIP name}?

C7Q03 (7.3)—Is (S.C.) covered by private health insurance, that is health insurance obtained through employment or unions or purchased directly?

C7Q03a—Does this private health insurance help pay for both doctor visits and hospital stays?

3. On December 19, 2000, two questions were added in households where the respondent was not the mother of the sampled child. The first asked the education of the sampled child’s mother (CQ10Q04A) and the second inquired whether she lived in the household (C2Q04_A).

4. On January 5, 2001, a new question—C7Q08B—was added to Section 7.

5. On February 2, 2001, open-ended text boxes were added to some existing questions in order to record verbatim answers from respondents whose answer did not clearly fit into the response categories provided. Text boxes were added to the following questions:

- C4Q0B
- C4Q02
- C4Q02B
- C4Q0501B
- C4Q0502B
- C4Q0503B
- C4Q0504B
- C4Q0505B

- C4Q0506B
- C4Q0507B
- C4Q0601B
- C4Q0602B
- C4Q0603B
- C5Q03A
- C7Q10
- C7Q15
- C12Q1
- C12Q1A
- C12Q4
- C12Q6A
- C12Q6B
- C12Q7B
- C13Q3
- C13Q4A
- C13Q4C
- C13Q61B
- C13Q62B
- C13Q63B
- C13Q64B
- C13Q65B
- C13Q66B
- C13Q67B

6. During the course of data collection and cleaning for the National Survey of Children with Special Health Care Needs, it became clear that children who were eligible for the National Immunization Survey (NIS), but who had not done the NIS interview, were being identified during the National Survey of CSHCN interview. On February 2, 2001, the CATI system was revised to return the interviewer to the NIS interview if one or more NIS-eligible children were identified during National Survey of CSHCN rostering.

7. On July 5, 2001, six new questions were added to Section 6:

- C6Q0A
- C6Q0A_A
- C6Q0A_B
- C6Q0B
- C6Q0C
- C6Q0D

8. On October 15, 2001, two questions were added to Section 12 on October 15, 2001:

- C12Q6C
- C12Q6COE

Appendix IV

Procedures for Assigning Household Poverty Status

The Department of Health and Human Services (DHHS) publishes Federal Poverty Guidelines for the determination of household poverty status. These guidelines are produced annually and developed separately for the 48 contiguous states (plus the District of Columbia), Alaska, and Hawaii. The National Survey of CSHCN used DHHS guidelines to assign household poverty status. Year 2000 guidelines were used with 1999 income for interviews conducted from October 17, 2000 through December 31, 2000, and with 2000 income for interviews conducted from January 1, 2001 through February 26, 2001 (Tables 17-19). Year 2001 guidelines were implemented on February 27, 2001 and used for the remainder of the data collection period (Tables 20-22). The tables were used to group households into the following poverty status categories:

- Category AA – Below 50% of Poverty
- Category A – Above 50% of Poverty but Below 100% of Poverty
- Category B – Above 100% of Poverty but Below 133% of Poverty
- Category C – Above 133% of Poverty but Below 150% of Poverty
- Category D – Above 150% of Poverty but Below 185% of Poverty
- Category E – Above 185% of Poverty but Below 200% of Poverty
- Category F – Above 200% of Poverty but Below 300% of Poverty
- Category G – Above 300% of Poverty but Below 400% of Poverty
- Category H – Above 400% of Poverty

Two variables were used to determine a National Survey of CSHCN household's poverty status: the number of people residing in a household and the household's income during the prior year. It was possible for income data to be gathered using one of three different methods during National Survey of CSHCN administration—a respondent could provide an exact income, provide an income range based on a closed-ended series of questions, or provide an income range using a set of cascade questions revised to allow exact determination of household poverty status in cases where that would not otherwise be possible. A brief description of each of these methods of gathering income data, and the household poverty status assignment process used for each appears below.

Respondent Reported Exact Income—When a respondent reported an exact income, poverty status was assigned by simply comparing the number of household members and the exact income reported with the appropriate guidelines table.

Respondent Reported Income Range Based on a Closed-Ended Series of Questions—When respondents did not supply a specific dollar amount for household income, it was necessary to go through a series of questions asking respondents whether the household income was below, exactly at, or above threshold amounts. A matrix was then created to categorize responses to these income cascade questions. Each cell in the matrix was assigned to one of the following income categories:

- Less than \$7,500
- \$7,500 to \$9,999

- \$10,000 to \$12,499
- \$12,500 to \$14,999
- \$15,000 to \$17,499
- \$17,500 to \$19,999
- \$20,000 to \$24,999
- \$25,000 to \$29,999
- \$30,000 to \$34,999
- \$35,000 to \$39,999
- \$40,000 to \$44,999
- \$45,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$74,999
- \$75,000 or higher

Respondents who went through the cascade of income questions were assigned a household income value that was the midpoint of their new income category as determined by their location in the matrix. Respondents with an income range of \$75,000 or higher were assigned an income value of \$100,000, based on the median income reported for such households during National Survey of CSHCN administration. Household poverty status was then assigned by comparing the number of household members and the assigned income amount with the appropriate guidelines table.

When respondents did not complete the income cascade, either because they refused or did not know the answer to one of the cascade questions, household poverty status could not be assigned. (It is worth noting, however, that households with unknown poverty status still qualified for the Low-Income Uninsured Supplement if the selected child was uninsured.)

Respondent Reported Income Range Based on Revised Series of Cascade Questions—In some cases, the income categories described above encompassed one or more income breaks for determining household poverty status. In such cases, additional income cascade questions beyond the standard set were asked in order to definitively assign poverty status. Respondents were assigned a household income value that was the midpoint of their new income category as determined by the additional income cascade question(s). For example, the income break indicating that a two-person household in the contiguous 48 states was below 50% of poverty, using the 2001 guidelines, was \$5,805. This income break is encompassed in the income category of “<\$7,500.” Therefore, an additional cascade question asked whether the household income was above, at, or below \$5,800 (based on rounding rules described in the notes to Tables 18-23). If the household reported an income below \$5,800, their assigned income value would be \$2,900, the midpoint of their income range based on answers to all of the cascade questions.

Once the household income value was determined, household poverty status was assigned by comparing the number of household members and the assigned income amount with the appropriate guidelines table.

Using DHHS guidelines, tables were developed to provide reference values for the additional income cascade questions. Due to a programming error, reference values using 1999 guidelines were inadvertently used with 1999 income from October 17, 2000 through December 31, 2000, and with 2000 income from January 1, 2001 through February 26, 2001. (Tables 23-25 present the reference values based on 1999 guidelines that were incorrectly used prior to February 26, 2001.) Poverty levels reported in the data file have been corrected to reflect the

correct 2000 guidelines for interviews conducted during these periods (see Tables 17-19). However, the exact poverty level could not be determined for 164 households because the 1999-guideline-based reference values do not perfectly map onto the 2000-guideline-based values.

Corrected reference values using 2001 guidelines with 2000 income were implemented on February 27, 2001 (Tables 26-28).

<< INSERT TABLES 17-28 ABOUT HERE >>

Table 17. Year 2000 guidelines for poverty ranges based on total family members for families in the 48 contiguous states and the District of Columbia

Family Size	Percent of Federal Poverty Level							
	50%	100%	133%	150%	185%	200%	300%	400%
2	\$5,625	\$11,250	\$14,963	\$16,875	\$20,813	\$22,500	\$33,750	\$45,000
3	\$7,075	\$14,150	\$18,820	\$21,225	\$26,178	\$28,300	\$42,450	\$56,600
4	\$8,525	\$17,050	\$22,677	\$25,575	\$31,543	\$34,100	\$51,150	\$68,200
5	\$9,975	\$19,950	\$26,534	\$29,925	\$36,908	\$39,900	\$59,850	\$79,800
6	\$11,425	\$22,850	\$30,391	\$34,275	\$42,273	\$45,700	\$68,500	\$91,400
7	\$12,875	\$25,750	\$34,248	\$38,625	\$47,638	\$51,500	\$77,250	\$103,000
8	\$14,325	\$28,650	\$38,105	\$42,975	\$53,003	\$57,300	\$85,950	\$114,600
9	\$15,775	\$31,550	\$41,962	\$47,325	\$58,368	\$63,100	\$94,650	\$126,200
10	\$17,225	\$34,450	\$45,819	\$51,675	\$63,733	\$68,900	\$103,350	\$137,800
11	\$18,675	\$37,350	\$49,676	\$56,025	\$69,098	\$74,700	\$112,050	\$149,400
12	\$20,125	\$40,250	\$53,533	\$60,375	\$74,463	\$80,500	\$120,750	\$161,000
13	\$21,575	\$43,150	\$57,390	\$64,725	\$79,828	\$86,300	\$129,450	\$172,600
14	\$23,025	\$46,050	\$61,247	\$69,075	\$85,193	\$92,100	\$138,150	\$184,200
15	\$24,475	\$48,950	\$65,104	\$73,425	\$90,558	\$97,900	\$146,850	\$195,800
16	\$25,925	\$51,850	\$68,961	\$77,775	\$95,923	\$103,700	\$155,550	\$207,400
17	\$27,375	\$54,750	\$72,818	\$82,125	\$101,288	\$109,500	\$164,250	\$219,000
18	\$28,825	\$57,650	\$76,675	\$86,475	\$106,653	\$115,300	\$172,950	\$230,600

Table 17

Table 18. Year 2000 guidelines for poverty ranges based on total family members for families in Alaska

Family Size	Percent of Federal Poverty Level							
	50%	100%	133%	150%	185%	200%	300%	400%
2	\$7,030	\$14,060	\$18,700	\$21,090	\$26,011	\$28,120	\$42,180	\$56,240
3	\$8,845	\$17,690	\$23,528	\$26,535	\$32,727	\$35,380	\$53,070	\$70,760
4	\$10,660	\$21,320	\$28,356	\$31,980	\$39,442	\$42,640	\$63,960	\$85,280
5	\$12,475	\$24,950	\$33,184	\$37,425	\$46,158	\$49,900	\$74,850	\$99,800
6	\$14,290	\$28,580	\$38,011	\$42,870	\$52,873	\$57,160	\$85,740	\$114,320
7	\$16,105	\$32,210	\$42,839	\$48,315	\$59,589	\$64,420	\$96,630	\$128,840
8	\$17,920	\$35,840	\$47,667	\$53,760	\$66,304	\$71,680	\$107,520	\$143,360
9	\$19,735	\$39,470	\$52,495	\$59,205	\$73,020	\$78,940	\$118,410	\$157,880
10	\$21,550	\$43,100	\$57,323	\$64,650	\$79,735	\$86,200	\$129,300	\$172,400
11	\$23,365	\$46,730	\$62,151	\$70,095	\$86,451	\$93,460	\$140,190	\$186,920
12	\$25,180	\$50,360	\$66,979	\$75,540	\$93,166	\$100,720	\$151,080	\$201,440
13	\$26,995	\$53,990	\$71,807	\$80,985	\$99,882	\$107,980	\$161,970	\$215,960
14	\$28,810	\$57,620	\$76,635	\$86,430	\$106,597	\$115,240	\$172,860	\$230,480
15	\$30,625	\$61,250	\$81,463	\$91,875	\$113,313	\$122,500	\$183,750	\$245,000
16	\$32,440	\$64,880	\$86,290	\$97,320	\$120,028	\$129,760	\$194,640	\$259,520
17	\$34,255	\$68,510	\$91,118	\$102,765	\$126,744	\$137,020	\$205,530	\$274,040
18	\$36,070	\$72,140	\$95,946	\$108,210	\$133,459	\$144,280	\$216,420	\$288,560

Table 18

Table 19. Year 2000 guidelines for poverty ranges based on total family members for families in Hawaii

Family Size	Percent of Federal Poverty Level							
	50%	100%	133%	150%	185%	200%	300%	400%
2	\$6,465	\$12,930	\$17,197	\$19,395	\$23,921	\$25,860	\$38,790	\$51,720
3	\$8,135	\$16,270	\$21,639	\$24,405	\$30,100	\$32,540	\$48,810	\$65,080
4	\$9,805	\$19,610	\$26,081	\$29,415	\$36,279	\$39,220	\$58,830	\$78,440
5	\$11,475	\$22,950	\$30,524	\$34,425	\$42,458	\$45,900	\$68,850	\$91,800
6	\$13,145	\$26,290	\$34,966	\$39,435	\$48,637	\$52,580	\$78,870	\$105,160
7	\$14,815	\$29,630	\$39,408	\$44,445	\$54,816	\$59,260	\$88,890	\$118,520
8	\$16,485	\$32,970	\$43,850	\$49,455	\$60,995	\$65,940	\$98,910	\$131,880
9	\$18,300	\$36,600	\$48,678	\$54,900	\$67,710	\$73,200	\$109,800	\$146,400
10	\$19,970	\$39,940	\$53,120	\$59,910	\$73,889	\$79,880	\$119,820	\$159,760
11	\$21,640	\$43,280	\$57,562	\$64,920	\$80,068	\$86,560	\$129,840	\$173,120
12	\$23,310	\$46,620	\$62,005	\$69,930	\$86,247	\$93,240	\$139,860	\$186,480
13	\$24,980	\$49,960	\$66,447	\$74,940	\$92,426	\$99,920	\$149,880	\$199,840
14	\$26,650	\$53,300	\$70,889	\$79,950	\$98,605	\$106,600	\$159,900	\$213,200
15	\$28,320	\$56,640	\$75,331	\$84,960	\$104,784	\$113,280	\$169,920	\$226,560
16	\$29,990	\$59,980	\$79,773	\$89,970	\$110,963	\$119,960	\$179,940	\$239,920
17	\$31,660	\$63,320	\$84,216	\$94,980	\$117,142	\$126,640	\$189,960	\$253,280
18	\$33,330	\$66,660	\$88,658	\$99,990	\$123,321	\$133,320	\$199,980	\$266,640

Table 19

Table 20. Year 2001 guidelines for poverty ranges based on total family members for families in the 48 contiguous states and the District of Columbia

Family Size	Percent of Federal Poverty Level							
	50%	100%	133%	150%	185%	200%	300%	400%
2	\$5,805	\$11,610	\$15,441	\$17,415	\$21,479	\$23,220	\$34,830	\$46,440
3	\$7,315	\$14,630	\$19,458	\$21,945	\$27,066	\$29,260	\$43,890	\$58,520
4	\$8,825	\$17,650	\$23,475	\$26,475	\$32,653	\$35,300	\$52,950	\$70,600
5	\$10,335	\$20,670	\$27,491	\$31,005	\$38,240	\$41,340	\$62,010	\$82,680
6	\$11,845	\$23,690	\$31,508	\$35,535	\$43,827	\$47,380	\$71,070	\$94,760
7	\$13,355	\$26,710	\$35,524	\$40,065	\$49,414	\$53,420	\$80,130	\$106,840
8	\$14,865	\$29,730	\$39,541	\$44,595	\$55,001	\$59,460	\$89,190	\$118,920
9	\$16,375	\$32,750	\$43,558	\$49,125	\$60,588	\$65,500	\$98,250	\$131,000
10	\$17,885	\$35,770	\$47,574	\$53,655	\$66,175	\$71,540	\$107,310	\$143,080
11	\$19,395	\$38,790	\$51,591	\$58,185	\$71,762	\$77,580	\$116,370	\$155,160
12	\$20,905	\$41,810	\$55,607	\$62,715	\$77,349	\$83,620	\$125,430	\$167,240
13	\$22,415	\$44,830	\$59,624	\$67,245	\$82,936	\$89,660	\$134,490	\$179,320
14	\$23,925	\$47,850	\$63,641	\$71,775	\$88,523	\$95,700	\$143,550	\$191,400
15	\$25,435	\$50,870	\$67,657	\$76,305	\$94,110	\$101,740	\$152,610	\$203,480
16	\$26,945	\$53,890	\$71,674	\$80,835	\$99,697	\$107,780	\$161,670	\$215,560
17	\$28,455	\$56,910	\$75,690	\$85,365	\$105,284	\$113,820	\$170,730	\$227,640
18	\$29,965	\$59,930	\$79,707	\$89,895	\$110,871	\$119,860	\$179,790	\$239,720

Table 20

Table 21. Year 2001 guidelines for poverty ranges based on total family members for families in Alaska

Family Size	Percent of Federal Poverty Level							
	50%	100%	133%	150%	185%	200%	300%	400%
2	\$7,255	\$14,510	\$19,298	\$21,765	\$26,844	\$29,020	\$43,530	\$58,040
3	\$9,145	\$18,290	\$24,326	\$27,435	\$33,837	\$36,580	\$54,870	\$73,160
4	\$11,035	\$22,070	\$29,353	\$33,105	\$40,830	\$44,140	\$66,210	\$88,280
5	\$12,925	\$25,850	\$34,381	\$38,775	\$47,823	\$51,700	\$77,550	\$103,400
6	\$14,815	\$29,630	\$39,408	\$44,445	\$54,816	\$59,260	\$88,890	\$118,520
7	\$16,705	\$33,410	\$44,435	\$50,115	\$61,809	\$66,820	\$100,230	\$133,640
8	\$18,595	\$37,190	\$49,463	\$55,785	\$68,802	\$74,380	\$111,570	\$148,760
9	\$20,485	\$40,970	\$54,490	\$61,455	\$75,795	\$81,940	\$122,910	\$163,880
10	\$22,375	\$44,750	\$59,518	\$67,125	\$82,788	\$89,500	\$134,250	\$179,000
11	\$24,265	\$48,530	\$64,545	\$72,795	\$89,781	\$97,060	\$145,590	\$194,120
12	\$26,155	\$52,310	\$69,572	\$78,465	\$96,774	\$104,620	\$156,930	\$209,240
13	\$28,045	\$56,090	\$74,600	\$84,135	\$103,767	\$112,180	\$168,270	\$224,360
14	\$29,935	\$59,870	\$79,627	\$89,805	\$110,760	\$119,740	\$179,610	\$239,480
15	\$31,825	\$63,650	\$84,655	\$95,475	\$117,753	\$127,300	\$190,950	\$254,600
16	\$33,715	\$67,430	\$89,682	\$101,145	\$124,746	\$134,860	\$202,290	\$269,720
17	\$35,605	\$71,210	\$94,709	\$106,815	\$131,739	\$142,420	\$213,630	\$284,840
18	\$37,495	\$74,990	\$99,737	\$112,485	\$138,732	\$149,980	\$224,970	\$299,960

Table 21

Table 22. Year 2001 guidelines for poverty ranges based on total family members for families in Hawaii

Family Size	Percent of Federal Poverty Level							
	50%	100%	133%	150%	185%	200%	300%	400%
2	\$6,680	\$13,360	\$17,769	\$20,040	\$24,716	\$26,720	\$40,080	\$53,440
3	\$8,415	\$16,830	\$22,384	\$25,245	\$31,136	\$33,660	\$50,490	\$67,320
4	\$10,150	\$20,300	\$26,999	\$30,450	\$37,555	\$40,600	\$60,900	\$81,200
5	\$11,885	\$23,770	\$31,614	\$35,655	\$43,975	\$47,540	\$71,310	\$95,080
6	\$13,620	\$27,240	\$36,229	\$40,860	\$50,394	\$54,480	\$81,720	\$108,960
7	\$15,355	\$30,710	\$40,844	\$46,065	\$56,814	\$61,420	\$92,130	\$122,840
8	\$17,090	\$34,180	\$45,459	\$51,270	\$63,233	\$68,360	\$102,540	\$136,720
9	\$18,825	\$37,650	\$50,075	\$56,475	\$69,653	\$75,300	\$112,950	\$150,600
10	\$20,560	\$41,120	\$54,690	\$61,680	\$76,072	\$82,240	\$123,360	\$164,480
11	\$22,295	\$44,590	\$59,305	\$66,885	\$82,492	\$89,180	\$133,770	\$178,360
12	\$24,030	\$48,060	\$63,920	\$72,090	\$88,911	\$96,120	\$144,180	\$192,240
13	\$25,765	\$51,530	\$68,535	\$77,295	\$95,331	\$103,060	\$154,590	\$206,120
14	\$27,500	\$55,000	\$73,150	\$82,500	\$101,750	\$110,000	\$165,000	\$220,000
15	\$29,235	\$58,470	\$77,765	\$87,705	\$108,170	\$116,940	\$175,410	\$233,880
16	\$30,970	\$61,940	\$82,380	\$92,910	\$114,589	\$123,880	\$185,820	\$247,760
17	\$32,705	\$65,410	\$86,995	\$98,115	\$121,009	\$130,820	\$196,230	\$261,640
18	\$34,440	\$68,880	\$91,610	\$103,320	\$127,428	\$137,760	\$206,640	\$275,520

Table 22

Table 23. Year 1999 reference value table for additional income cascade questions for families in the 48 contiguous states and the District of Columbia

Family Size	Reported Range of Household Income														
	<\$7,500	\$7,500- \$9,999	\$10,000- \$12,499	\$12,500- \$14,999	\$15,000- \$17,499	\$17,500- \$19,999	\$20,000- \$24,999	\$25,000- \$29,999	\$30,000- \$34,999	\$35,000- \$39,999	\$40,000- \$44,999	\$45,000- \$49,999	\$50,000- \$59,999	\$60,000- \$74,999	\$75,000+
2	5,500	A	11,100	B	16,600	D	22,100	F	33,200	G	G	H	H	H	H
3	6,900	A	A	13,900	B	18,500	D	27,800	F	F	41,700	G	55,500	H	H
4	AA	8,400	A	A	16,700	B	22,200	D	30,900 / 33,400	F	F	F	G	66,800	H
5	AA	AA	A	A	A	19,500	B	26,000	D	36,100 / 39,000	F	F	58,600	G	80,000
6	AA	AA	11,200	A	A	A	22,300	B	33,500	D	41,300	F	F	67,000	90,000
7	AA	AA	AA	A	A	A	A	B	33,500	37,700	D	46,500	F	F	100,000
8	AA	AA	AA	14,000	A	A	A	28,000	B	37,200	42,000	D	51,800 / 56,000	F	85,000 / 110,000
9	AA	AA	AA	AA	AA	A	A	A	B	B	41,000	46,200	57,000	61,600	90,000 / 125,000
10	AA	AA	AA	AA	16,800	A	A	A	33,600	B	B	C	D	62,200 / 67,200	100,000 / 135,000
11	AA	AA	AA	AA	AA	18,200	A	A	A	36,400	B	48,500	54,700	67,400 / 72,900	110,000 / 145,000
12	AA	AA	AA	AA	AA	AA	A	A	A	A	B	B	52,200 / 59,000	72,600	80,000 / 120,000
13	AA	AA	AA	AA	AA	AA	21,000	A	A	A	42,100	B	56,000	63,200	85,000 / 125,000
14	AA	AA	AA	AA	AA	AA	22,500	A	A	A	A	B	B	67,400	90,000 / 135,000
15	AA	AA	AA	AA	AA	AA	23,900	A	A	A	A	47,700	B	63,400 / 71,600	95,000 / 145,000
16	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	B	67,200	100,000 / 150,000
17	AA	AA	AA	AA	AA	AA	AA	26,700	A	A	A	A	53,400	71,000	105,000 / 160,000
18	AA	AA	AA	AA	AA	AA	AA	28,100	A	A	A	A	56,200	B	110,000 / 170,000

Note: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?"") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$500 from either endpoint of the reported range of household income. When income was greater than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household income was entirely within one poverty range. The poverty range to which each letter refers is listed in the text.

Table 23

Table 24. Year 1999 reference value table for additional income cascade questions for families in Alaska

Family Size	Reported Range of Household Income														
	<\$7,500	\$7,500- \$9,999	\$10,000- \$12,499	\$12,500- \$14,999	\$15,000- \$17,499	\$17,500- \$19,999	\$20,000- \$24,999	\$25,000- \$29,999	\$30,000- \$34,999	\$35,000- \$39,999	\$40,000- \$44,999	\$45,000- \$49,999	\$50,000- \$59,999	\$60,000- \$74,999	\$75,000+
2	6,900	A	A	13,800	B	18,400	C	27,700	F	F	41,500	G	55,400	H	H
3	AA	8,700	A	A	B	B	23,100	26,000	32,200	F	F	F	52,100	69,600	H
4	AA	AA	A	A	A	A	20,900	27,800	31,400	38,700	41,800	F	F	62,700	80,000
5	AA	AA	A	A	A	A	B	B	32,500	36,600	D	48,800	F	73,200	100,000
6	AA	AA	AA	14,000	A	A	A	27,900	B	37,100	41,900	D	51,700 / 55,800	F	85,000 / 110,000
7	AA	AA	AA	AA	15,700	A	A	A	31,400	B	41,800	47,100	58,200	62,800	95,000 / 125,000
8	AA	AA	AA	A	A	A	A	B	B	B	B	46,500	52,400	64,800 / 70,000	105,000 / 140,000
9	AA	AA	AA	AA	AA	19,200	A	A	A	38,500	B	B	51,200 / 57,700	71,200	75,000 / 115,000
10	AA	AA	AA	AA	AA	AA	21,000	A	A	A	42,000	B	55,900	63,000	85,000 / 125,000
11	AA	AA	AA	AA	AA	AA	22,800	A	A	A	B	B	B	68,300	90,000 / 135,000
12	AA	AA	AA	AA	AA	AA	A	A	A	A	A	49,000	B	73,600 / 65,200	100,000 / 145,000
13	AA	AA	AA	AA	AA	AA	AA	26,300	A	A	A	A	52,600	69,900	105,000 / 160,000
14	AA	AA	AA	AA	AA	AA	AA	28,000	A	A	A	A	56,100	B	110,000 / 170,000
15	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	B	B	B	120,000 / 180,000
16	AA	AA	AA	AA	AA	AA	AA	AA	31,600	A	A	A	B	63,100	125,000 / 190,000
17	AA	AA	AA	AA	AA	AA	AA	AA	33,300	A	A	A	A	66,600	135,000 / 200,000
18	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	A	70,200	140,000 / 210,000

Note: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?"") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$500 from either endpoint of the reported range of household income. When income was greater than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household income was entirely within one poverty range. The poverty range to which each letter refers is listed in the text.

Table 24

Table 25. Year 1999 reference value table for additional income cascade questions for families in Hawaii

Family Size	Reported Range of Household Income														
	<\$7,500	\$7,500- \$9,999	\$10,000- \$12,499	\$12,500- \$14,999	\$15,000- \$17,499	\$17,500- \$19,999	\$20,000- \$24,999	\$25,000- \$29,999	\$30,000- \$34,999	\$35,000- \$39,999	\$40,000- \$44,999	\$45,000- \$49,999	\$50,000- \$59,999	\$60,000- \$74,999	\$75,000+
2	6,400	A	A	A	16,900	19,100	23,500	E	F	38,200	G	H	50,900	H	H
3	AA	8,000	A	A	16,000	B	21,200 / 24,000	D	31,900	F	F	47,900	G	63,900	H
4	AA	AA	A	A	A	19,200	B	28,800	C	38,400	F	F	57,600	G	75,000
5	AA	AA	11,200	A	A	A	22,500	C	33,700	D	41,500	E	F	67,400	90,000
6	AA	AA	AA	AA	A	A	A	B	C	38,500	D	47,500	51,400	F	75,000 / 105,000
7	AA	AA	AA	14,500	A	A	A	28,900	B	38,500	43,400	D	53,500 / 57,900	F	85,000 / 115,000
8	AA	AA	AA	A	16,100	A	A	B	32,200	B	42,800	48,300	D	64,300	95,000 / 130,000
9	AA	AA	AA	AA	AA	AA	A	A	A	A	B	47,100	53,100	65,500 / 70,800	105,000 / 140,000
10	AA	AA	AA	AA	AA	19,300	A	A	A	38,700	B	B	51,400 / 58,000	71,500	75,000 / 115,000
11	AA	AA	AA	AA	AA	AA	20,900	A	A	A	41,900	B	55,700	62,800	85,000 / 125,000 /
12	AA	AA	AA	AA	AA	AA	22,600	A	A	A	A	A	B	67,700	90,000 / 135,000
13	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	48,400	B	64,300 / 72,600	95,000 / 145,000
14	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	B	51,600	68,600	105,000 / 155,000
15	AA	AA	AA	AA	AA	AA	AA	27,400	A	A	A	B	54,900	73,000	100,000 / 165,000
16	AA	AA	AA	AA	AA	AA	AA	29,000	A	A	A	A	58,100	B	115,000 / 175,000
17	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	A	61,300	125,000 / 185,000
18	AA	AA	AA	AA	AA	AA	AA	AA	32,300	A	A	A	A	64,600	130,000 / 195,000

Note: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$500 from either endpoint of the reported range of household income. When income was greater than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household income was entirely within one poverty range. The poverty range to which each letter refers is listed in the text.

Table 25

Table 26. Year 2001 reference value table for additional income cascade questions for families in the 48 contiguous states and the District of Columbia

Family Size	Reported Range of Household Income														
	<\$7,500	\$7,500-\$9,999	\$10,000-\$12,499	\$12,500-\$14,999	\$15,000-\$17,499	\$17,500-\$19,999	\$20,000-\$24,999	\$25,000-\$29,999	\$30,000-\$34,999	\$35,000-\$39,999	\$40,000-\$44,999	\$45,000-\$49,999	\$50,000-\$59,999	\$60,000-\$74,999	\$75,000+
2	5,800	A	11,600	B	C	D	21,500 / 23,200	F	F	G	G	46,400	H	H	H
3	AA	A	A	A	B	B	21,900	27,100	F	F	43,900	G	58,500	H	H
4	AA	8,800	A	A	A	B	23,500	26,500	32,700	F	F	F	53,000	70,600	H
5	AA	AA	A	A	A	A	B	27,500	31,000	38,200	41,300	F	F	62,000	85,000
6	AA	AA	11,800	A	A	A	23,700	B	31,500	D	43,800	47,400	F	71,100	95,000
7	AA	AA	AA	13,400	A	A	A	26,700	B	C	D	D	53,400	F	80,000 / 105,000
8	AA	AA	AA	AA	A	A	A	A	B	B	C	D	55,000	F	90,000 / 120,000
9	AA	AA	AA	AA	16,400	A	A	A	32,800	B	43,600	C	D	65,500	100,000 / 130,000
10	AA	AA	AA	AA	AA	A	A	A	A	B	B	47,600	53,700	66,200 / 71,500	105,000 / 145,000
11	AA	AA	AA	AA	AA	19,400	A	A	A	38,800	B	B	51,600 / 58,200	71,800	80,000 / 115,000
12	AA	AA	AA	AA	AA	AA	A	A	A	A	41,800	B	55,600	62,700	85,000 / 125,000
13	AA	AA	AA	AA	AA	AA	22,400	A	A	A	A	B	B	67,200	90,000 / 135,000
14	AA	AA	AA	AA	AA	AA	23,900	A	A	A	A	47,900	B	63,600 / 71,800	95,000 / 145,000
15	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	A	B	67,700	100,000 / 155,000
16	AA	AA	AA	AA	AA	AA	AA	26,900	A	A	A	A	53,900	71,700	110,000 / 160,000
17	AA	AA	AA	AA	AA	AA	AA	28,500	A	A	A	A	56,900	B	115,000 / 170,000
18	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	A	B	120,000 / 180,000

Note: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$500 from either endpoint of the reported range of household income. When income was greater than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household income was entirely within one poverty range. The poverty range to which each letter refers is listed in the text.

Table 26

Table 27. Year 2001 reference value table for additional income cascade questions for families in Alaska

Family Size	Reported Range of Household Income														
	<\$7,500	\$7,500- \$9,999	\$10,000- \$12,499	\$12,500- \$14,999	\$15,000- \$17,499	\$17,500- \$19,999	\$20,000- \$24,999	\$25,000- \$29,999	\$30,000- \$34,999	\$35,000- \$39,999	\$40,000- \$44,999	\$45,000- \$49,999	\$50,000- \$59,999	\$60,000- \$74,999	\$75,000+
2	AA	A	A	A	B	19,300	21,800	26,800 / 29,000	F	F	43,500	G	58,000	H	H
3	AA	9,100	A	A	A	18,300	B	27,400	33,800	36,600	F	F	54,900	73,200	H
4	AA	AA	11,000	A	A	A	22,100	B	33,100	D	E	F	F	66,200	90,000
5	AA	AA	AA	A	A	A	A	B	B	38,800	D	47,800	51,700	F	80,000 / 105,000
6	AA	AA	AA	AA	A	A	A	A	B	B	C	D	54,800	F	90,000 / 120,000
7	AA	AA	AA	AA	16,700	A	A	A	33,400	B	B	C	C	61,800 / 66,800	100,000 / 135,000
8	AA	AA	AA	AA	AA	18,600	A	A	A	37,200	B	B	55,800	68,800	110,000 / 150,000
9	AA	AA	AA	AA	AA	AA	A	A	A	A	41,000	B	54,500	61,500	80,000 / 125,000
10	AA	AA	AA	AA	AA	AA	22,400	A	A	A	A	B	B	67,100	90,000 / 135,000
11	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	48,500	B	64,500 / 72,800	95,000 / 145,000
12	AA	AA	AA	AA	AA	AA	AA	26,200	A	A	A	A	52,300	69,600	105,000 / 155,000
13	AA	AA	AA	AA	AA	AA	AA	28,000	A	A	A	A	56,100	B	110,000 / 170,000
14	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	A	B	120,000 / 180,000
15	AA	AA	AA	AA	AA	AA	AA	AA	31,800	A	A	A	A	63,700	130,000 / 190,000
16	AA	AA	AA	AA	AA	AA	AA	AA	33,700	A	A	A	A	67,400	135,000 / 200,000
17	AA	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	71,200	140,000 / 215,000
18	AA	AA	AA	AA	AA	AA	AA	AA	AA	37,500	A	A	A	A	150,000 / 225,000

Note: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$500 from either endpoint of the reported range of household income. When income was greater than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household income was entirely within one poverty range. The poverty range to which each letter refers is listed in the text.

Table 27

Table 28. Year 2001 reference value table for additional income cascade questions for families in Hawaii

Family Size	Reported Range of Household Income														
	<\$7,500	\$7,500- \$9,999	\$10,000- \$12,499	\$12,500- \$14,999	\$15,000- \$17,499	\$17,500- \$19,999	\$20,000- \$24,999	\$25,000- \$29,999	\$30,000- \$34,999	\$35,000- \$39,999	\$40,000- \$44,999	\$45,000- \$49,999	\$50,000- \$59,999	\$60,000- \$74,999	\$75,000+
2	6,700	A	A	13,400	B	C	D	26,700	F	F	G	G	53,400	H	H
3	AA	8,400	A	A	16,800	B	22,400	D	31,100 / 33,700	F	F	F	G	67,300	H
4	AA	AA	A	A	A	A	B	27,000	D	37,600	F	F	F	G	80,000
5	AA	AA	11,900	A	A	A	23,800	B	31,600	D	44,000	47,500	F	71,300	95,000
6	AA	AA	AA	13,600	A	A	A	27,200	B	36,200	D	D	54,500	F	80,000 / 110,000
7	AA	AA	AA	AA	A	A	A	A	B	B	C	46,100	56,800	61,400	90,000 / 125,000
8	AA	AA	AA	AA	AA	A	A	A	A	B	B	C	51,300	63,200 / 68,400	105,000 / 135,000
9	AA	AA	AA	AA	AA	18,800	A	A	A	37,700	B	B	56,500	69,700	115,000 / 150,000
10	AA	AA	AA	AA	AA	AA	A	A	A	A	41,100	B	54,700	61,700	80,000 / 125,000
11	AA	AA	AA	AA	AA	AA	22,300	A	A	A	A	B	B	66,900	90,000 / 135,000
12	AA	AA	AA	AA	AA	AA	24,000	A	A	A	A	48,100	B	63,900 / 72,100	95,000 / 145,000
13	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	A	51,500	68,500	105,000 / 155,000
14	AA	AA	AA	AA	AA	AA	AA	27,500	A	A	A	A	55,000	73,200	110,000 / 165,000
15	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	58,500	B	115,000 / 175,000
16	AA	AA	AA	AA	AA	AA	AA	AA	31,000	A	A	A	A	61,900	125,000 / 185,000
17	AA	AA	AA	AA	AA	AA	AA	AA	32,700	A	A	A	A	65,400	130,000 / 200,000
18	AA	AA	AA	AA	AA	AA	AA	AA	AA	A	A	A	A	68,900	140,000 / 205,000

Note: When the reported range of household income was included within two or more poverty ranges, additional questions (W9Q12 and W9Q12A) were asked to determine the poverty range for the household. Values within the body of this table represent the border between two poverty ranges. Additional income questions were asked with this value ("Would you say this income was above or below {value}?") to identify the proper poverty range for the household. Values were rounded to the nearest \$100 if income was below \$75,000 and to the nearest \$5,000 if income was over \$75,000. When income was less than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$500 from either endpoint of the reported range of household income. When income was greater than \$20,000, the additional income questions were not asked if the value (i.e., the range border) was less than \$900 from either endpoint of the reported range of household income. Letters rather than values signify that the reported range of household income was entirely within one poverty range. The poverty range to which each letter refers is listed in the text.

Table 28

Appendix V

Advance Letters

Letter used in 2000 with NIS sample—

FROM THE DIRECTOR
NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the U.S. Department of Health and Human Services. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

Your participation is likely to require only one or two minutes of your time. You may call our toll-free telephone number (1-800-290-1296) to participate immediately or visit the study's web site at <http://www.cdc.gov/nis> to learn more about the study. If you have a child between 1 and 3 years of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study. If your household is selected, the interview should take only about fifteen minutes to complete.

This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

Letter used in 2001 with NIS sample—

FROM THE DIRECTOR
NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the U.S. Department of Health and Human Services. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

The results of this study also help local, state, and federal health authorities understand how to improve health care services for all children. Therefore, some households may be asked questions about the types of health and related services their children need or use.

You may call the study's toll-free telephone number (1-800-290-1296) to participate immediately or to obtain more information about the study's background and content. You may also visit the study's web site at <http://www.cdc.gov/nis> for more information. If you have a child between 18 and 35 months of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

Letter used in 2002 with NIS sample—

FROM THE DIRECTOR
NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household will be called to take part in an important national study being conducted by the U.S. Department of Health and Human Services. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

The results of this study also help local, state, and federal health authorities understand how to improve health care services for all children. Therefore, some households may be asked questions about the types of health and related services their children need or use.

You may call Jim Murphy at the study's toll-free telephone number (1-800-247-1970) to participate immediately or to obtain more information about the study's background and content. You may also visit the study's web site at <http://www.cdc.gov/nis> for more information. If you have a child between 18 and 35 months of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead. If you would like to learn more about your rights as a respondent, please contact the Chair of the Institutional Review Board at 1-800-223-8118.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-247-1970 be called.

Letter used 2000-2002 with augmentation sample—

FROM THE DIRECTOR
NATIONAL CENTER FOR HEALTH STATISTICS

Within the next few weeks, your household may be called to take part in an important national study about the health of children and teenagers. The survey is being conducted by the U.S. Department of Health and Human Services.

We are relying on your help to make this study a success. Local, state, and federal health authorities depend on the results of this study to measure the progress of health care for the country. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only.

You may call our toll-free telephone number (1-800-290-1296) to participate immediately or visit the study's web site at <http://www.cdc.gov/nis> to learn more about the study. This study has been approved by the NCHS Institutional Review Board. If you have questions about your rights as a study participant, you may call Margot Palmer, Institutional Review Board chairman, toll-free at 1-800-223-8118.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-290-1296 be called.

Appendix VI

Disposition Code Frequencies and Response Rate Calculations

<< INSERT TABLES 29 AND 30 ABOUT HERE >>

Table 29. Frequencies of disposition codes for National Survey of CSHCN

Disposition code by name	Disposition Category	Frequency	Percent of Total
No Contact	UH	178,910	6.83%
3+ Fax/Modem Prior to Any Contact	Z	51,388	1.96%
2+ Temporarily Not in Service	Z	35,813	1.37%
Nonworking Number	Z	197,250	7.53%
Number Changed	Z	15,354	0.59%
Answering Machine - Known Household	UOC	2,545	0.10%
Answering Machine - Nonresidential	Z	17,909	0.68%
Answering Machine - Residential Status Unknown	UH	38,213	1.46%
Answering Service - Known Household	Z	5	< 0.005%
Answering Service - Nonresidential	Z	209	0.01%
Answering Service - Residential Status Unknown	UH	154	0.01%
Spanish Case - Residential Status Unknown	UH	260	0.01%
Other Language Case - Residential Status Unknown	UH	573	0.02%
Physical/Mental Impairment Case - Residential Status Unknown	UH	306	0.01%
Appointment at Introduction - Residential Status Unknown	UH	4,260	0.16%
Callback at Introduction - Residential Status Unknown	UH	467	0.02%
Broken Appointment at Introduction - Residential Status Unknown	UH	4,727	0.18%
Hangup During Introduction	UH	20,688	0.79%
Refusal at Introduction	UH	80,647	3.08%
Callback - Known Household	UOC	4,350	0.17%
Appointment - Known Household	UOC	1,089	0.04%
Broken Appointment - Known Household	UOC	2,131	0.08%
Refusal - Known Household	UOC	32,831	1.25%
NIS-Level Callback	UOS	318	0.01%
NIS-Level Appointment	UOS	221	0.01%
NIS-Level - Broken Appointment	UOS	144	0.01%
NIS-Level Refusal	UOS	2,520	0.10%
Not Residential	Z	115,646	4.41%
Refusal Prior to NS-CSHCN Item C2Q01	UOS	35,942	1.37%
Callback Prior to NS-CSHCN Item C2Q01	UOS	4,633	0.18%
Appointment Prior to NS-CSHCN Item C2Q01	UOS	3,411	0.13%
Refusal Prior to NS-CSHCN Item FACCT1	UOS	7,336	0.28%
Callback Prior to NS-CSHCN Item FACCT1	UOS	596	0.02%
Appointment Prior to NS-CSHCN Item FACCT1	UOS	713	0.03%
Refusal Prior to NS-CSHCN Item FACCT5	UOS	169	0.01%
Callback Prior to NS-CSHCN Item FACCT5	UOS	106	< 0.005%
Appointment Prior to NS-CSHCN Item FACCT5	UOS	81	< 0.005%
Refusal Prior to NS-CSHCN Item C8Q01	R	1,564	0.06%
Callback Prior to NS-CSHCN Item C8Q01	R	262	0.01%
Appointment Prior to NS-CSHCN Item C8Q01	R	244	0.01%
Refusal - Partial Interview	P	259	0.01%
Callback - Partial Interview	P	21	< 0.005%
Broken Appointment - Partial Interview	P	6	< 0.005%
Appointment - Partial Interview	P	42	< 0.005%
Other Language Case - Known Household, Unknown Age Eligibility	UOC	1,026	0.04%
Other Language Case - Known Age-Eligible Household	Y	1,263	0.05%
Screened - Emancipated Minor Household ¹	XC	198	0.01%
Screened - No Age-Eligible Children	XC	620,924	23.70%
Screened Age-Eligible Household in Missouri Supplemental Sample, No Child Sampled ²	XS	2,496	0.10%
Completed Household Interview	I	180,967	6.91%
Converted Household Interview	I	11,026	0.42%
GENESYS-Resolved Numbers	Z	938,271	35.81%
Total		2,620,484	100.00%

¹Interviews were not conducted in households in which no one over the age of 17 resided.²Only special-needs interviews were conducted in the Missouri Supplemental Sample.

Table 29

Table 30. Unweighted response rate calculations for National Survey of CSHCN

	Frequency or calculated rate	Code or formula
<i>Summary of disposition categories</i>		
Completed Interviews at the Household-Level	191,993	I
Partial Interviews at the Household-Level	328	P
Unknown Residential Status	329,205	UH
Known Household, Unknown Age Eligibility	43,972	UOC
Known Age-Eligible Household, Unknown Special Needs Eligibility	56,190	UOS
Refusal, Screened and Eligible	2,070	R
Screened for Age-Eligibility, No Eligible Child	621,122	XC
Screened for Special Needs, No Child Sampled	2,496	XS
Known Age-Eligible Household, Other Language	1,263	Y
Out of Scope (i.e., Business, Nonworking, Fax/Modem)	1,371,845	Z
Total	2,620,484	
<i>Calculation of response rates</i>		
Interview Completion Rate (ICR)	98.3%	$(I+P) / (I+P+R)$
Special-Needs Screener Completion Rate (SNSCR)	77.4%	$(I+P+R+XS) / (I+P+R+XS+Y+UOS)$
		$(I+P+R+Y+UOS+XS+XC) /$
Age Screener Completion Rate (ASCR)	95.2%	$(I+P+R+Y+UOS+XS+XC+UOC)$
		$(I+P+R+Y+UOS+XS+XC+UOC+Z) /$
Resolution Rate (RR)	87.4%	$(I+P+R+Y+UOS+XS+XC+UOC+Z+UH)$
CASRO Rate	63.4%	$(ICR)(SNSCR)(ASCR)(RR)$

Appendix VII

National Survey of CSHCN: Pretest II

Because the National Survey of CSHCN was to share the same sampling frame as the NIS, with NIS administration occurring prior to administration of the National Survey of CSHCN, it was important that acceptable response rates for both studies be obtained. Lower than anticipated response rates, for both the NIS and the National Survey of CSHCN, were observed in the first National Survey of CSHCN pretest. The interview completion rate was 97.0%, the screener completion rate was 79.9%, and the resolution rate was 87.8%. The CASRO response rate, derived from the product of the three rates described above, was 68.0%. In comparison, the CASRO response rate for the NIS across the 11 IAP areas used in the first pretest was 73.4%. (It should be noted that, in contrast to the main study, a single screener completion rate was calculated for the pretests. This screener completion rate, which combines the two stages of eligibility determination, artificially inflates the overall response rate. Because this incorrect calculation was not detected until well after the conclusion of both pretests, it has not been recalculated here.)

Therefore, a second pretest was designed to identify a method of integrating the NIS and the National Survey of CSHCN that would achieve acceptable response rates for both projects. Because the low response rates for the first pretest were primarily a result of increased breakoffs at the beginning of NIS administration, it was decided that the second pretest should concentrate on methods that would increase response at this early stage—that is, improvements to the advance letter and introductory script text. To investigate a full range of alternatives to increase NIS and National Survey of CSHCN response rates, four letter conditions and three introductory script conditions were tested. The individual advance letter and introductory script conditions were joined to create seven advance letter/introductory script combinations, described below.

NIS Advance Letter and NIS Introduction (Control Group)—In this control condition, the advance letter already in use for the NIS was mailed to households with an identified address. The current NIS introductory script was administered.

No Advance Letter and Low-Content Introductory Script—No advance letters were mailed to households regardless of whether they had an identified address. A low-content introductory script (mentioning only that the study was about children and teenagers in the respondent's state) was administered.

No Advance Letter and High-Content Introductory Script—No advance letters were mailed to households regardless of whether they had an identified address. A high-content introductory script (which explicitly stated that the study was about children and teenagers with special health needs, and included information about the random selection of numbers for the study and its expected length in most households) was administered.

Revised NIS Advance Letter 1 and Low-Content Introductory Script—An advance letter specifically describing the content of both the NIS and the National Survey of CSHCN interviews and omitting mention of the NIS age-eligibility range was mailed to households with

an identified address. A low-content introductory script (mentioning only that the study was about children and teenagers in the respondent's state) was administered.

Revised NIS Advance Letter 1 and High-Content Introductory Script—An advance letter specifically describing the content of both the NIS and the National Survey of CSHCN interviews and omitting mention of the NIS age-eligibility range was mailed to households with an identified address. A high-content introductory script (which explicitly stated that the study was about children and teenagers with special health needs, and included information about the random selection of numbers for the study and its expected length in most households) was administered.

Revised NIS Advance Letter 2 and Low-Content Introductory Script—A “generic” advance letter, describing the content of the interview more generally, was mailed to households with an identified address. A low-content introductory script (mentioning only that the study was about children and teenagers in the respondent's state) was administered.

Revised NIS Advance Letter 2 and High-Content Introductory Script—A “generic” advance letter, describing the content of the interview more generally, was mailed to households with an identified address. A high-content introductory script (which explicitly stated that the study was about children and teenagers with special health needs, and included information about the random selection of numbers for the study and its expected length in most households) was administered.

The advance letters used in Pretest II appear in Appendix VIII. The introductory texts used were as follows:

NIS Introductory Script—“Hello, my name is {name of interviewer}. I'm calling on behalf of the Centers for Disease Control and Prevention. We're conducting a nationwide immunization study to find out how many children under 4 years of age are receiving all of the recommended vaccinations for childhood diseases. Your telephone number has been selected at random to be included in the study. The questions I have will take only a few minutes.”

Low-Content Introductory Script—“Hi, my name is {name of interviewer}. I am calling on behalf of the Centers for Disease Control and Prevention and the National Center for Health Statistics. We are doing a survey about the health of children and teenagers in {name of state}.”

High-Content Introductory Script—“Hi, my name is {name of interviewer}. I am calling on behalf of the Centers for Disease Control and Prevention and the National Center for Health Statistics. We are doing a nationwide study about the special health needs of children and teenagers. Your number has been selected at random to be included in the study. For most people, the questions I have will take only a few minutes.”

Pretest II Sample Design and Selection

The Pretest II sample consisted of four national replicates created for NIS administration, drawn in the manner described in Chapter II of this report. One replicate was used for the

control group. The other three replicates were used for the experimental conditions. Each of the three experimental replicates was first assigned to an advance letter condition. Then, each of these replicates was split into two half-replicates, with one half-replicate assigned to the low-content introduction group and the other half-replicate assigned to the high-content introduction group, resulting in a total of six independent samples with the control group sample comprising a seventh.

The Pretest II sample was designed so that response rates for the four individual letter conditions and three individual introductory script conditions could be examined, although it should be noted that each is confounded with its partnered letters or scripts. With a minimum sample of 20,000 lines and a one-sided test at a 5% level of significance, it was anticipated that the following differences would be detectable with 80% power:

- A decrease of 0.46 percentage points in the NIS age-eligibility rate assuming a current eligibility rate of 3.8%. The age-eligibility rate is defined as the percent of households that contain a child who is age-eligible for the study (i.e., a child between 19 and 35 months of age).
- A decrease of 1.2 percentage points in the NIS CASRO response rate assuming a current rate of 70%.

As mentioned earlier, the low response rates observed in Pretest I were primarily a result of increased breakoffs at the beginning of NIS administration, and therefore, the second pretest concentrated on methods that would increase response at this early stage. Thus, the experiment was designed to examine differences in NIS response rates rather than National Survey of CSHCN response rates. An increase in response at the NIS-level would also benefit the National Survey of CSHCN, because it would mean that households were being successfully identified and initially screened.

It is important to note that because national replicates created for the NIS were used for Pretest II, the sample did not perfectly mirror the expected sample for the main National Survey of CSHCN. The NIS sample focuses equally on each of the 78 IAP areas (50 states, plus 28 metropolitan areas) while the National Survey of CSHCN was designed to provide representative state-level estimates. Therefore, using national replicates created for the NIS meant that the pretest used more urban sample than would be used for the main study.

In a cost-saving effort, 75% of the pretest sample was flagged for an abbreviated special-needs interview that would include only the early questionnaire sections. In addition, children without special needs were not sampled for health insurance control sample interviews and Low-Income Uninsured Supplement interviews were not administered in this portion of the sample. This plan allowed for the full sample to be used in evaluating advance letters and introductory scripts, while providing a formal “dress rehearsal” of the full special-needs interview, the health insurance control sample interview and the Low-Income Uninsured Supplement in 25% of the sample. In this 25% of the sample, children without special needs were subsampled from every other household with such children.

Pretest II Training

The data collection staff for the second pretest of the National Survey of CSHCN were identified during August 2000. A total of 219 interviewers in the Abt Associates Chicago and Las Vegas telephone centers were identified based on their NIS experience, interviewing skills, supervisor evaluations, and production rates on the NIS. Training was conducted in both

Chicago and Las Vegas to ensure full coverage of interviewing hours (9:00 A.M. - 9:00 P.M. in each time zone).

Each interviewer administered only one variant of the introduction. During training, particular attention was paid to ensuring that the interviewers delivered the different introductions in the same way, to minimize any effect due to the confounding of interviewer and introduction. The specific purposes of the second pretest were communicated to interviewers.

Pretest II Data Collection

For the experimental groups where an advance letter was used, an address was matched to 45.9% of the sampled telephone numbers. It is important to note that, since not all households could be matched with an address, there were households in each of the experimental conditions (as well as 100% of the no-letter experimental condition) that were not mailed an advance letter.

Data collection began on August 9, 2000 and ended on November 13, 2000. A total of 10,116 households with children were screened, resulting in 2,265 special-needs interviews (1,682 abbreviated interviews and 583 full-length interviews), and 1,988 health insurance control sample interviews. A total of 124 Low-Income Uninsured Supplement interviews were also completed.

A Spanish-language version of the CATI questionnaire was incorporated into Pretest II. From 819 known eligible households where Spanish was the primary language, 705 completed the special-needs screening. From these 705 households, 186 households had children sampled for an interview and 176 completed the interview for their sampled children. A total of 78 interviews regarding a child with special health care needs and 97 health insurance control sample interviews were completed (4.1% of total interviews conducted). Twenty-eight Low-Income Uninsured Supplement interviews were completed in these households.

Pretest II Overall Response Rates

In addition to response rates by experimental condition, overall response rates for the total combined Pretest II sample were calculated. The interview completion rate, a measure of completed interviews among eligible respondents, was 97.4%. The screener completion rate, which measures the number of known households identified as having an eligible respondent, was 85.1%. The resolution rate, indicating the proportion of telephone numbers that could be identified as residential or non-residential, was 87.4%. The CASRO response rate, derived from the product of the three rates described above, was 72.5%. (As before, it should be noted that, in contrast to the main study, a single screener completion rate was calculated for this pretest. This screener completion rate, which combines the two stages of eligibility determination, artificially inflates the overall response rate. Because the results of this pretest were evaluated and decisions were made using this incorrect calculation, it has not been recalculated here.)

Pretest II Results

Details regarding NIS and National Survey of CSHCN response rates by condition observed in the second pretest are provided in Table 31. Rates are provided for each of the seven advance letter-introductory script combinations, followed by rates for each experimental letter and introductory script group individually.

Tests of statistical significance were performed comparing individual letter and introductory script groups. When comparing the NIS introduction with the alternative introductions, all differences in the key indicators between the control and experimental groups were significant. When comparing the NIS advance letter with the no letter condition, all differences in the key indicators between the two groups were significant except for the NIS age-eligibility rate. When comparing the NIS advance letter with the revised advance letter conditions, all differences in the key indicators between the control and the experimental groups were significant except for the NIS age-eligibility rate and the resolution rate.

Based on the significant differences in key indicators between the control group and each of the experimental groups, it was concluded that the NIS advance letter and introduction were the most beneficial for both National Survey of CSHCN and NIS response rates, and this combination was selected for National Survey of CSHCN use.

<< INSERT TABLE 31 ABOUT HERE >>

Additional Testing (CSHCN Screener Question Order)

While the purpose of the second pretest was to investigate alternatives to increase NIS and National Survey of CSHCN response rates, an additional test was incorporated to address a concern raised during analysis of Pretest I data.

During Pretest I, the order of administration for the CSHCN Screener and QuICCC-R was alternated. The first question of both screening instruments asked whether the sampled child used prescription medication. Regardless of screener order, several respondents reported during the first screener that their children did not use prescription medication and then contradicted themselves during the second screener, reporting that the children did in fact use prescription medication. Because administration of the screeners was preceded with a somewhat lengthy introduction (see Table 2), it was hypothesized that it may have been cognitively difficult for respondents to move directly from the introduction to the first screening question, thus resulting in the apparent underreporting of prescription medication use during administration of the initial screening instrument.

To determine whether prescription medication reporting differed based on the location of the question relative to the introduction (i.e., just after the screener introduction vs. later in the screener), the order of the first and second questions on the CSHCN Screener (selected for use based on Pretest I results) were alternated during Pretest II. One of these questions assessed prescription drug use and the other assessed the child's need for or use of more medical services than most children of the same age.

Pretest results suggested that the location of the prescription medication item did not have a significant effect on the overall proportion of children identified as using prescription medications, or as having a special health care need. However, when respondents were asked about prescription drug use immediately following the screener introduction, the proportion of children identified with special health care needs varied significantly across the advance letter/introductory script treatment conditions that were part of the pretest. The lowest rate occurred in the group who received the current NIS advance letter and introductory script, which were ultimately chosen for use in the main study.

When the item regarding use of medical services was asked first, no significant difference was found in the proportion of CSHCN identified across the letter/introduction treatment groups.

In addition, administering the item regarding use of medical services immediately following the screener introduction resulted in a significant increase in the proportion of CSHCN with “above average need/use of services” and who “need/use specialized therapies.” Based on these results, a decision was made to administer the item regarding use of medical services first, followed by the prescription medication item, during the main study.

Table 31. Response rates and eligibility rates for the National Immunization Survey and the National Survey of CSHCN, by experimental condition (Pretest II)

Experimental Condition	NIS Response Rates					National Survey of CSHCN Response Rates			Eligibility Rates	
	Sample Size	Interview Completion Rate	Screening Completion Rate	Resolution Rate	CASRO Response Rate	Interview Completion Rate	Screening Completion Rate	CASRO Response Rate	Percent of Households that include NIS-Eligible Children	Percent of Households with Children that include CSHCN
CONTROL GROUP: NIS Letter and Introduction	22,537	90.0%	95.8%	81.7%	70.5%	98.7%	91.1%	73.5%	3.7%	21.5%
No Letter and Low-Content Introductory Script	10,928	82.0%	88.7%	80.4%	58.5%	96.8%	82.0%	63.8%	3.7%	24.7%
No Letter and High-Content Introductory Script	10,929	89.9%	91.4%	78.8%	64.7%	98.2%	84.9%	65.7%	4.0%	23.4%
Revised NIS Letter 1 and Low-Content Introductory Script	11,119	87.4%	89.5%	81.8%	64.0%	98.6%	83.9%	67.7%	3.1%	23.7%
Revised NIS Letter 1 and High-Content Introductory Script	11,118	88.8%	92.5%	80.2%	65.9%	98.3%	86.9%	68.5%	4.0%	22.7%
Revised NIS Letter 2 and Low-Content Introductory Script	11,002	93.5%	89.6%	81.5%	68.3%	99.0%	83.8%	67.6%	3.3%	23.6%
Revised NIS Letter 2 and High-Content Introductory Script	11,002	90.8%	92.6%	79.9%	67.2%	96.8%	86.3%	66.7%	3.6%	22.6%
No Letter	21,857	86.1%	90.0%	79.6%	61.6%	97.5%	83.5%	64.8%	3.8%	24.0%
Revised NIS Letter 1	22,237	88.2%	91.0%	81.0%	65.0%	98.4%	85.5%	68.1%	3.5%	23.2%
Revised NIS Letter 2	22,004	92.1%	91.1%	80.8%	67.7%	97.9%	85.2%	67.4%	3.5%	23.1%
Low-Content Introductory Script	33,049	87.4%	89.3%	81.3%	63.4%	98.1%	83.4%	66.5%	3.4%	24.0%
High-Content Introductory Script	33,049	89.8%	92.1%	79.6%	65.9%	97.8%	86.2%	67.1%	3.9%	22.9%

Table 31

Appendix VIII

Pretest II Advance Letters

NIS Advance Letter—

Within the next few weeks, your household will be called to take part in an important national study being conducted by the U.S. Department of Health and Human Services. This study provides important information for measuring the progress of vaccination for young children for the country.

Childhood immunization rates are at an all-time high of 78%, but many children have not received all of their immunizations. The Department of Health and Human Services is committed to improving immunization services and reducing the costs of vaccines. Local, state, and federal health authorities depend on the results of this study to measure the progress of immunization for the country.

Your participation is likely to require only one or two minutes of your time. You may call our toll-free telephone number (1-800-247-1970) to participate immediately or visit the study's web site at <http://www.cdc.gov/nis> to learn more about the study. If you have a child between 1 and 3 years of age, please take a moment to locate the child's immunization records. They will help you during the interview.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate. The information we are gathering will help shape health care policy in the years ahead.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household is eligible for participation in this study. If your household is selected, the interview should take only about fifteen minutes to complete.

This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-247-1970 be called.

Revised NIS Advance Letter 1—

As part of an important study conducted by the United States Department of Health and Human Services (DHHS), parents nationwide are being interviewed over the telephone about the health of their children. The interview includes questions about vaccinations, types of medical care received, prescription medicines, allergies, and health insurance. The information you provide will help shape health care policy in the years ahead.

Within the next few weeks, your household may be called to take part in this study. Your telephone number was selected at random using scientific methods and your address was obtained through commercial listings.

We are relying on your help to make this study a success. Although participation is completely voluntary and there is no penalty for not answering any question, we hope you will agree to participate.

This survey is authorized by the Public Health Service Act. All of your answers will be kept confidential. The answers from all survey participants will be combined into summary reports and used only for statistical research. No identifying information will be reported. You may end the interview at any time.

If you have any questions about the study, please call our toll-free number, 1-877-248-7501, or visit the study's web site at <http://www.cdc.gov/nis> to learn more about the study. This study has been approved by the National Center for Health Statistics Institutional Review Board. If you have questions about your rights as a study participant, you may call Margot Palmer, Institutional Review Board chairman, toll-free at 1-800-223-8118.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-877-248-7501 be called.

Revised NIS Advance Letter 2—

Within the next few weeks, your household will be called to take part in an important study being conducted by the U.S. Department of Health and Human Services. Parents nationwide are being interviewed over the telephone about the health of their children. The interview includes questions about vaccinations, medical services, childcare, and health insurance.

The information collected by this survey will be used by government agencies, universities, private health planners, and researchers to study the health care needs of America's children. By participating in this important survey, you will help provide better information for health policy and decisions.

You may call our toll-free number (1-800-247-1970) to participate immediately or visit the study's web site at <http://www.cdc.gov/nis> to learn more about the study. If you have a child between 1 and 3 years of age, you may be asked about your child's immunizations. Please take a moment to locate your child's immunization records. They will help during the interview.

Your telephone number was selected at random using scientific methods, and your address was obtained through commercial listings. When the interviewer calls, you will be asked a few questions to determine whether or not your household will be selected for participation in the study.

This study is authorized by the Public Health Service Act [Secs. 306 & 2102 (a)(7)], and by law, information you provide during the interview will be kept strictly confidential. The information reported in this survey will be summarized for research purposes only so that you and your family cannot be identified. Participation is voluntary and will in no way affect any benefits you may receive now or in the future. You may end the interview at any time.

We appreciate your taking the time to talk to us. Thank you for your assistance.

Sincerely,

Edward J. Sondik, Ph.D.
Director

If you prefer to contact us using a TTY, please call the AT&T Relay Service at 1-800-682-8786 and request that 1-800-247-1970 be called.

Appendix IX

Key Prevalence Estimates and Weighted Frequencies

<< INSERT TABLES 32 AND 33 ABOUT HERE >>

Table 32. Unweighted and weighted estimates of the frequency and prevalence of households with CSHCN

Location	Total Unweighted Number of Households	Total Weighted Estimate of Number of Households	Unweighted Number of Households with CSHCN	Weighted Estimate of the Number of Households with CSHCN	Standard Error of Weighted Estimate of the Number of Households with CSHCN	Percentage of Households with Children that Include CSHCN	Standard Error of Percentage of Households with Children that Include CSHCN
Alabama	3,843	633,444	764	128,384.1	5,071.360	20.27	0.768
Alaska	4,333	96,262	761	16,759.2	623.014	17.41	0.636
Arizona	4,276	706,420	774	125,950.2	4,939.268	17.83	0.680
Arkansas	3,655	376,447	768	81,294.3	3,028.444	21.60	0.775
California	4,967	4,666,965	778	793,879.0	31,707.077	17.01	0.652
Colorado	4,129	605,002	763	115,817.1	4,456.595	19.14	0.710
Connecticut	3,469	456,829	762	100,739.3	3,704.060	22.05	0.786
Delaware	3,339	108,184	772	24,862.2	938.677	22.98	0.835
D. C.	4,048	60,669	777	12,478.7	508.119	20.57	0.791
Florida	4,135	2,052,306	773	405,145.1	16,952.106	19.74	0.779
Georgia	4,077	1,209,738	777	228,355.1	9,193.101	18.88	0.733
Hawaii	4,976	154,238	765	25,343.3	1,007.897	16.43	0.628
Idaho	4,049	187,960	757	34,904.6	1,368.840	18.57	0.707
Illinois	4,027	1,683,295	765	323,385.4	14,146.332	19.21	0.796
Indiana	3,553	842,524	767	183,905.2	6,941.184	21.83	0.793
Iowa	3,948	384,040	771	75,289.9	2,803.407	19.61	0.707
Kansas	3,400	372,452	770	86,440.7	3,128.578	23.21	0.809
Kentucky	3,412	567,572	762	127,375.1	4,760.529	22.44	0.810
Louisiana	3,235	651,799	774	151,439.6	6,040.651	23.23	0.885
Maine	3,124	167,301	755	39,333.3	1,379.351	23.51	0.811
Maryland	3,345	751,470	774	173,068.4	6,343.585	23.03	0.822
Massachusetts	3,434	814,749	761	181,455.3	7,281.694	22.27	0.850
Michigan	3,485	1,355,895	766	300,110.4	10,988.474	22.13	0.788
Minnesota	3,612	667,350	756	136,852.6	5,388.661	20.51	0.779
Mississippi	4,005	419,057	776	84,063.5	3,495.872	20.06	0.789
Missouri	6,742	770,775	1536	173,632.4	4,600.748	22.53	0.577
Montana	4,006	120,562	751	23,299.7	865.823	19.33	0.697
Nebraska	3,777	231,836	768	47,614.8	1,803.694	20.54	0.750
Nevada	4,553	287,274	765	51,011.7	1,971.186	17.76	0.661
New Hampshire	3,320	170,341	765	39,811.7	1,462.115	23.37	0.827
New Jersey	4,107	1,142,576	765	223,660.0	8,865.841	19.58	0.743
New Mexico	4,170	266,856	773	50,301.7	2,095.472	18.85	0.750
New York	4,308	2,494,162	773	462,147.4	17,556.401	18.53	0.681
North Carolina	3,624	1,132,102	755	237,136.1	9,288.362	20.95	0.787
North Dakota	3,949	83,510	760	16,449.8	631.460	19.70	0.727
Ohio	3,597	1,539,570	782	338,567.2	12,078.835	21.99	0.763
Oklahoma	3,589	483,309	764	106,428.1	4,324.220	22.02	0.843
Oregon	3,650	455,481	760	96,743.4	3,771.786	21.24	0.794
Pennsylvania	3,874	1,566,146	774	300,574.9	11,170.738	19.19	0.699
Rhode Island	3,378	135,746	766	31,025.5	1,191.991	22.86	0.843
South Carolina	3,647	568,473	765	119,183.6	4,569.295	20.97	0.775
South Dakota	4,120	101,639	759	18,483.8	705.079	18.19	0.678
Tennessee	3,567	799,368	763	167,617.2	6,404.127	20.97	0.779
Texas	4,088	3,110,501	773	583,509.0	22,055.947	18.76	0.693
Utah	3,896	331,674	765	66,071.6	2,398.220	19.92	0.706
Vermont	3,312	81,301	763	19,395.0	727.064	23.86	0.853
Virginia	3,288	985,680	768	224,547.9	8,316.849	22.78	0.820
Washington	3,517	819,364	768	177,725.1	6,504.591	21.69	0.776
West Virginia	3,441	231,759	765	53,722.7	2,189.630	23.18	0.890
Wisconsin	3,642	712,887	763	147,604.2	5,451.389	20.71	0.745
Wyoming	3,850	67,694	768	13,787.5	514.528	20.37	0.736
TOTAL U.S.	196,888	38,682,554	39,865	7,746,683.7	59,768.613	20.03	0.149

Table 32

Table 33. Unweighted and weighted estimates of the frequency and prevalence of CSHCN

Location	Total Unweighted Number of Children	Total Weighted Estimate of Number of Children	Unweighted Number of CSHCN	Weighted Estimate of Number of CSHCN	Standard Error of Weighted Estimate of Number of CSHCN	Percentage of Children who have Special Health Care Needs	Standard Error of Percentage of Children who have Special Health Care Needs
Alabama	6,904	1,132,020	924	152,002.4	6,729.029	13.43	0.551
Alaska	8,548	194,247	937	20,370.0	854.941	10.49	0.430
Arizona	8,542	1,434,674	962	157,990.5	7,180.266	11.01	0.482
Arkansas	6,616	688,509	927	95,906.8	4,126.521	13.93	0.565
California	9,662	9,484,792	966	972,200.9	48,319.738	10.25	0.484
Colorado	7,864	1,140,139	923	133,069.5	5,677.519	11.67	0.470
Connecticut	6,411	855,619	914	120,033.4	4,759.956	14.03	0.535
Delaware	6,181	199,440	953	30,653.0	1,363.888	15.37	0.639
D. C.	7,400	114,868	968	15,926.9	827.626	13.87	0.666
Florida	7,572	3,775,238	935	488,853.7	22,178.755	12.95	0.540
Georgia	7,479	2,238,948	943	284,533.2	12,947.542	12.71	0.550
Hawaii	9,382	298,093	968	30,131.6	1,483.429	10.11	0.470
Idaho	8,366	378,378	939	42,563.3	1,844.147	11.25	0.467
Illinois	7,761	3,287,379	921	385,269.3	17,931.580	11.72	0.516
Indiana	6,744	1,590,441	933	224,877.5	9,592.838	14.14	0.566
Iowa	7,766	735,994	943	90,507.3	3,555.994	12.30	0.466
Kansas	6,517	720,762	957	107,233.8	4,564.219	14.88	0.601
Kentucky	6,032	1,000,165	934	156,766.9	6,298.521	15.67	0.609
Louisiana	5,964	1,219,590	948	190,570.5	8,847.058	15.63	0.681
Maine	5,646	300,788	911	46,807.6	1,778.366	15.56	0.567
Maryland	6,161	1,386,935	950	213,004.8	8,750.668	15.36	0.603
Massachusetts	6,411	1,522,314	924	222,606.0	10,186.076	14.62	0.635
Michigan	6,637	2,615,150	951	363,853.3	15,417.736	13.91	0.567
Minnesota	6,946	1,305,743	899	162,755.9	7,089.900	12.46	0.520
Mississippi	7,374	778,905	945	99,866.5	4,716.183	12.82	0.569
Missouri	12,824	1,443,854	1927	218,400.1	6,502.165	15.13	0.423
Montana	7,652	231,520	897	27,230.5	1,122.831	11.76	0.471
Nebraska	7,420	453,494	945	58,494.3	2,473.096	12.90	0.518
Nevada	8,911	558,465	910	60,225.0	2,619.934	10.78	0.445
New Hampshire	6,127	314,751	923	47,814.2	2,027.132	15.19	0.604
New Jersey	7,506	2,130,620	948	275,616.6	12,524.651	12.94	0.555
New Mexico	8,110	517,933	927	56,927.1	2,617.827	10.99	0.490
New York	8,030	4,752,409	944	562,536.4	24,446.333	11.84	0.487
North Carolina	6,432	2,019,342	884	281,233.4	11,921.415	13.93	0.551
North Dakota	7,527	159,507	912	19,783.5	845.938	12.40	0.498
Ohio	6,844	2,900,609	959	405,608.8	16,447.313	13.98	0.542
Oklahoma	6,684	900,135	949	131,586.2	5,980.559	14.62	0.618
Oregon	6,905	864,911	912	115,367.4	4,972.209	13.34	0.549
Pennsylvania	7,322	2,941,751	970	382,719.8	16,011.706	13.01	0.519
Rhode Island	6,134	251,131	930	36,413.5	1,473.942	14.50	0.561
South Carolina	6,662	1,022,128	932	137,612.3	5,546.581	13.46	0.524
South Dakota	8,213	203,539	928	23,075.0	930.779	11.34	0.439
Tennessee	6,338	1,424,737	899	199,913.1	8,264.735	14.03	0.555
Texas	7,848	6,048,116	950	719,014.0	30,706.411	11.89	0.489
Utah	8,850	732,952	979	81,785.0	3,374.303	11.16	0.440
Vermont	6,064	148,562	923	23,167.3	981.887	15.59	0.621
Virginia	5,826	1,773,139	921	273,770.8	11,152.661	15.44	0.606
Washington	6,629	1,553,745	917	217,705.5	8,637.589	14.01	0.540
West Virginia	6,034	397,797	924	66,240.0	3,228.673	16.65	0.734
Wisconsin	6,948	1,381,019	955	185,697.9	7,531.171	13.45	0.513
Wyoming	7,448	128,330	950	16,176.3	654.598	12.61	0.489
TOTAL U.S.	372,174	73,653,627	48,690	9,432,468.6	84,301.531	12.81	0.109

Table 33